INFORMATION NEEDS, INFORMATIONAL SUPPORT AND PSYCHOSOCIAL ADJUSTMENT IN PERSONS WITH HEAD AND NECK CANCER

BARBARA ADAMS

INFORMATION NEEDS, INFORMATIONAL SUPPORT AND PSYCHOSOCIAL ADJUSTMENT IN PERSONS WITH HEAD AND NECK CANCER

by

Barbara Adams

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ABSTRACT

Head and neck cancer has been described as one of the most emotionally traumatic types of cancer. Individuals often cope with stressful events by seeking information. However, recent studies have reported that information was identified as an unmet need by persons with cancer. There has been very little published research that explored the specific information needs of persons with head and neck cancer or that investigated outcomes of informational support.

This descriptive correlational study investigated information needs, informational support and psychosocial adjustment in a convenience sample of 65 persons with head and neck cancer. Based on the time since diagnosis, the sample was divided into three subgroups, representing different phases of the cancer experience. Data were collected by interviewing outpatients at the local ambulatory cancer centre and a few inpatients in the acute care facility. A structured questionnaire, consisting primarily of rating scales and structured questions, was developed by the researcher and used for data collection.

The findings indicated that 75% of the sample wanted to be well informed. The importance and type of information needed varied throughout the phases of the cancer experience and differed significantly ($p = .0005$) among the three subgroups. Participants expressed a high level of

satisfaction with informational support received and, in general, adjusted well to their head and neck cancer. A significant positive correlation ($p = .02$) between informational support and psychosocial adjustment was found in two of the subgroups.

This study identified phase-specific information needs of persons with head and neck cancer that can guide nurses in their patient teaching, and thereby facilitate the process of psychosocial adjustment. The results of this study can be used in basic and continuing education programs to illustrate the changing nature of information needs and the importance of ongoing assessment. This study paves the way for future studies to investigate similar needs in other populations, explore different intervention approaches, or evaluate outcomes of various modes of information delivery.

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CHAPTER I

Introduction

Head and neck cancer has been described as being more emotionally traumatic than any other type of cancer (Dropkin, 1989; Mah & Johnston, 1993). The fears of cancer are often compounded by the burden of having to cope with the effects of treatments that result in facial disfigurement and/or disruption to basic functions such as speaking or eating. Additionally, persons with head and neck cancer are usually older, often have a long history of chronic alcoholism or excessive smoking, and may possess poor adaptive coping skills (Breitbart & Holland, 1988; Cachin, 1989; Dropkin, 1989). All of these factors make them a psychologically vulnerable group. Studies of this population have cited a variety of adjustment problems including reduced self-esteem, social isolation (Breitbart & Holland, 1988; Dropkin, 1989; Gamba et al., 1992; Pruyn et al., 1986), and suicidal tendencies (Bolund, 1985; Hietanen & Lonnqvist, 1991).

Coping with cancer is an ongoing process, characterized by several phases, each with its unique problems and needs (Mages & Mendelsohn, 1979; Mullan, 1985; Weisman, 1979). Over a period of time persons with cancer are confronted with a series of threats of varying intensity and duration (Mages & Mendelsohn, 1979). Survival rates for head and neck cancer are relatively good (Shah & Lydiatt, 1995), so

people with this type of cancer may live for extended periods of time.

Lazarus and Folkman (1984) postulated that information seeking is a primary mode individuals use to cope with a life threatening or potentially disabling illness. Research studies have suggested that patients who were completely satisfied with the information they received were less anxious, coped better, and had fewer adjustment problems (Goldberg & Cullen, 1985; Leino-Kilpi, Iire, Suominen, Vuoreheimo, & Valimaki, 1993; Teasdale, 1993).

The Problem

In Newfoundland there are approximately 100 new individuals diagnosed with head and neck cancer each year (Newfoundland Cancer Treatment and Research Foundation, 1994). As previously mentioned, persons with head and neck cancer have needs that are often challenging and are different from other persons with cancer involving other sites. It was perceived that the psychosocial needs of patients with head and neck cancer were not being fully addressed. Prior to this study, the group was targeted for enhanced program planning. It was also noted that, in general, and especially in Newfoundland, the needs of persons with head and neck cancer had received limited research attention.

Studies recently conducted in Newfoundland and across Canada, reported that persons with cancer, including head and neck cancer, identified a widespread need for more and better information (Canadian Cancer Society, 1992; Paulse, unpublished document, 1994).

A thorough computer search of the nursing, medical, and psychosocial literature was conducted before initiating this study. The search revealed a number of studies that investigated the psychosocial aspects of head and neck cancer. Most studies focused on the identification and description of problems rather than on interventions and outcomes of care (Bunston & Mings, 1994; Gamba et al., 1992; Koster & Bergsma, 1990; Rapoport, Kreitler, Chaitchik, Algor, & Weissler, 1993; Watt-Watson & Graydon, 1995). There was a paucity of studies that explored the specific information needs of persons with head and neck cancer. During the conduct of this study, one research paper on this topic was published (Glavassevich, McKibbon, & Thomas, 1995). Findings indicated that even though patients were given some information, they felt inadequately prepared for surgery the postoperative course.

Recognizing the importance of expanding the current body of knowledge in psychosocial oncology, in 1994, the National Cancer Institute of Canada (NCIC) set priorities for areas of new research. These included, the changing needs of persons with cancer (by site), how the needs of

persons with cancer are being met, and the impact of different psychosocial interventions on the quality of life (National Cancer Institute of Canada, unpublished manuscript, 1994).

Leino-Kilpi et al. (1993) reviewed the existing body of research concerning various aspects of patient information. They concluded that although there had been fairly extensive research into the information needs of persons with cancer, little was published on the effectiveness of patient education and very little was known about the specific needs of persons with different types of cancer and at different disease phases.

In summary, four separate but interrelated areas were identified as needing further consideration: 1) a need for enhanced program planning to meet the psychosocial concerns of person with head and neck cancer, 2) a need expressed by persons with all types of cancer for more and better information, 3) a paucity of published research that addressed the information needs of persons with head and neck cancer, and 4) a recommendation by NCIC that the changing needs of persons with site-specific cancers be investigated. On the basis of these identified needs, this study was proposed.

Purposes of Study

The purposes of this study were to identify the specific information needs of persons with head and neck cancer at three key phases of the cancer experience, to ascertain the degree of satisfaction with informational support received, to assess psychosocial adjustment to cancer, and to explore the relationship between the level of satisfaction with informational support received and psychosocial adjustment.

Rationale for Study

The need for information has been identified as an area for further research. Information is especially important, considering the changes taking place within the health care system. There is increasing emphasis on self-care and the patient's right to self-determination (Leino-Kilpi et al., 1993). At the same time, shorter hospital stays are limiting the time for teaching patients and assisting them with the coping process (Baker, 1992; Dropkin, 1989; Watt-Watson & Graydon, 1995). Teaching time must be used to best advantage and meet identified needs. However, nurses and patients' perceptions of information needs often differ (Bunston & Mings, 1995; Griffiths & Leek, 1995; Luker et al., 1995, Suominen, Leino-Kilpi, & Laippala, 1994). There is also increasing emphasis on the need to validate nursing interventions, and show that they result in positive

outcomes (Canadian Council on Health Facilities Accreditation, 1994).

This study was designed to yield data that could increase nurses' understanding of the information needs and psychosocial adjustment of persons with head and neck cancer, at three phases of the cancer experience. The data could be used to guide nurses in the provision of information to these patients. The study would highlight areas of informational support that need continued emphasis or that require change. If a positive relationship between informational support and psychosocial adjustment could be shown, it would be an additional incentive for nurses to ensure that patients' information needs were addressed.

Although the study would have particular relevance to Newfoundland, the results could guide program planning elsewhere. The findings would ultimately expand the body of knowledge in psychosocial oncology, and yield data that could be further analyzed to provide even more information about a subpopulation of persons with cancer that has thus far received limited research attention.

Research Questions

The specific research questions were:

1. What are the information needs of persons with head and neck cancer: a) following diagnosis,

b) following completion of treatment, and c) during rehabilitation and continuing care?

2. What is the quality of informational support perceived by persons with head and neck cancer?
3. How well do persons with head and neck cancer adjust to their illness: a) following diagnosis, b) following completion of treatment, and c) during rehabilitation and continuing care?
4. Is there a relationship between the perceived quality of informational support received and psychosocial adjustment in persons with head and neck cancer?

CHAPTER II

Literature Review

This review is divided into sections that reflect the major study variables: psychosocial adjustment, information needs, and informational support. The review begins with a discussion of literature related to cancer in general, and subsequently focuses on literature that deals with head and neck cancer.

The Cancer Experience

The Psychosocial Impact of Cancer

A diagnosis of cancer has been described as "the ultimate existential crisis" (McGee, 1993, p. 438). With few exceptions, it elicits life and death fears, followed by a prolonged period of uncertainty (Bolund, 1990; Krause, 1991, McGee, 1993). Cancer causes one's whole psychological adjustment to be in severe turmoil (Cohen & Lazarus, 1979). Ware (1991) conceptualized that cancer affects four dimensions of well-being: general health perceptions, personal functioning, psychological functioning, and social/role functioning. Although the majority of patients manage to adapt to their disease, cancer creates psychosocial needs that patients often find difficult to cope with and resolve (Bolund, 1990; Bunston & Mings, 1995; Taylor, 1983).

A complete understanding of the impact of cancer requires an assessment of adjustment (Olsen, Perry, Rohe, & Keith, 1995). Psychosocial adjustment has been described as a dynamic and multidimensional concept that relates to the process whereby an individual's equilibrium is re-established to either its pre-illness state or a new state, which could be either higher or lower than its previous state (Bloom, 1984). In the past two decades, treatment advances have increased cancer survival. Cancer is now seen as a chronic illness or an illness with a treatable acute phase and possible recurrence. Living with cancer is a continual process that requires ongoing adjustment and integration of the changing demands and tasks of the illness process (Derogatis, 1986; Hiem, 1990; Mishel, 1988).

Weisman (1979) proposed that the cancer experience consisted of four psychosocial phases, from diagnosis to deterioration or decline. Each phase was characterized by varying levels of psychosocial vulnerability. Problems differed from phase to phase and varied among different site specific groups of persons with cancer.

Similar phases were later described by Mullan (1985), a physician, following his personal experience dealing with a diagnosis of cancer. He viewed the cancer experience as being characterized by three "seasons of survival". The first season, "acute survival", began with the cancer

diagnosis and was dominated by diagnostic and therapeutic efforts to stem the course of disease. Fear and anxiety were constant and important elements of this phase. The second season, "extended survival", began when the disease went into remission or had completed the basic course of treatment. This was a phase of watchful waiting, dominated by fear of recurrence. The patient was no longer supported by the health care setting and had to start fending for himself or herself. The third season, "permanent survival", had no distinct beginning but evolved into a period when the activity of the disease or the likelihood of its return was sufficiently small that the disease might be considered arrested. This was a period when the secondary effects of cancer treatment might be the primary concern and when persons could be challenged by employment problems. These "seasons of survival" have provided a useful framework for observing the changing nature of the cancer experience and gaining insight into how persons with cancer can be supported through the cancer continuum (Hassey-Dow, 1990).

Several researchers examined psychosocial changes over time in persons with cancer. Frank-Stromborg and Wright (1984) conducted a cross-sectional study in a sample of 320 patients with cancers of various sites and at different disease phases. Contrary to their expectation, findings indicated that there were no psychosocial areas that changed

with a cancer diagnosis in the majority of patients. The authors noted a "disturbing finding was the frequency that patients described the inability to discuss problems with the nurse because of little nurse-patient contact" (p. 128).

Longitudinal studies were conducted by Ell, Nishimoto, Morvay, Mantell and Hamovitch (1989) in a sample of 253 patients with newly diagnosed breast, colo-rectal and lung cancer, and Northouse (1990) in a sample of 41 newly diagnosed breast cancer patients. In contrast to Frank-Stromborg and Wright's (1984) findings, the investigators found that a subgroup of cancer patients were at higher risk of long-term adjustment problems. Ell et al. noted that declining psychological adaptation was related more to an erosion of coping resources than to illness-related factors. Northouse identified that difficulties were primarily in the areas of vocational, domestic, and social roles and suggested that further research was needed to explore risk factors and determine what kind of resources patients need.

A number of authors asserted that the adjustment process was strongly dependent on the mediating process of coping. Coping resources included intrapsychic or affect-management processes, such as cognitive appraisal and emotional responses; and behavioral or action-oriented processes, such as social support and information-seeking (Hiem, 1990; Lazarus 1993; Lazarus & Folkman, 1984; Mishel,

1988). Information-seeking has been proposed as a primary means of coping with a stressful situation and a major area of importance for persons with cancer (Lazarus & Folkman, 1984; Mishel, 1988; Northouse & Northouse, 1987).

Information Needs and Cancer

Although providing information to patients has been considered a critical component of care, the assumption has been that nurses know what patients need to know (Agre, Bookbinder, Cirrincione, & Keating, 1990; Luker et al., 1995; Redman, 1993). Lenz (1984) found that in spite of a desire to acquire information, patients often felt they were unsuccessful in obtaining the information they needed, particularly from health professionals who held mistaken views of what or how much they wanted to know. Several studies have reported incongruence between nurses' and cancer patients' perceptions of information needs (Bunston & Mings, 1995; Griffiths & Leek, 1995; Luker et al., 1995, Suominen et al., 1994). Luker et al. (1995) asserted that because of the fear and apprehension associated with cancer, it was particularly important that people with cancer received the right amount and type of information.

Studies exploring information and participation preferences among persons with cancer found that most individuals wanted maximum information about their illness and treatments (Brandt, 1991; Cassileth, Zupkis, Sutton-

Smith, & March, 1980; Davison, Degner, & Morgan, 1995; Degner & Sloan, 1992; Hack, Degner, & Dyck, 1994). Findings regarding participation preferences have not been as consistent. Some studies reported that most respondents preferred an active role in decision-making (Brandt, 1991; Cassileth et al., 1980; Hack et al., 1994), while others found that the majority preferred a passive role (Davison et al., 1995; Degner & Sloan, 1992). It was suggested that factors such as age, gender, and time from diagnosis may influence participation preferences.

Cassileth et al. (1980) reported one of the first studies exploring the types of information desired by persons with cancer. Their sample consisted of 256 patients with cancers of various sites and at differing disease phases. Findings indicated that the greatest information needs included issues surrounding the nature of the disease and treatment, side effects, and prognosis. Later studies, supported these findings. In their study of the discharge information needs of 40 patients treated surgically for lung cancer, Galloway, Bubela, McKibbon, McCay and Ross (1993) found that a moderately high amount of information was needed and information relating to treatment, prevention of complications and management of symptoms was most important. Similarly, Davison et al. (1995) reported that the majority of their sample of 57 men with recently diagnosed prostate

cancer, desired a fair bit to almost everything about their disease, treatment, self-care and social activity.

Derdiarian (1987a, 1987b) conducted a study in a sample of 60 persons newly diagnosed with various types of cancer. Data were gathered using the 144 item Derdiarian Informational Needs Assessment. The findings indicated a hierarchical pattern of information needs. Information related to treatment, prognosis and diagnosis was most important; information related to physical and psychological well-being, job and goals was of moderate importance; and information related to family and social relationships ranked lower but was still important. Gender, age and disease stage were found to influence both the amount and type of information needed.

The Canadian Cancer Society (1992) assessed the information needs of almost 2000 persons with cancer, from across Canada. Reported needs were similar to the previously described studies, but also included how to deal with the medical system and hospital procedures, resources that provide help, possible emotional reactions to cancer and its treatment, possible impact on roles and lifestyle, and how to cope with changes. The study reported that the need for information far outweighed its availability and accessibility.

Informational Support and Adjustment to Cancer

Informational support is one type of social support and refers to the provision of information, such as advice, suggestion, or feedback about how the person is doing, that the person can use in coping with personal and environmental problems (House & Kahn, 1985). Although there has been considerable research on social support, the emphasis on informational support has been limited (Stewart, 1989). It is often embedded in other psychosocial issues, and has been assessed as a secondary or incidental factor, rather than as a central variable (Northouse & Northouse, 1987).

Telch and Telch (1985) reviewed the research on education as an intervention with cancer patients. They noted that the emphasis was on providing information as a way of coping with the psychological consequences. This approach assumed that patients' anxieties or fears would automatically decrease with increased knowledge and access to information. Following a review of the research on information and anxiety, Teasdale (1993) noted that findings were inconsistent, and concluded that the theory that information relieved anxiety, appeared to be an oversimplification.

In a study of women with breast cancer, Brolin Hopkins (1986) found no significant relationship between information-seeking and adaptational outcomes. Similarly,

following their study of satisfaction with communication, and coping style, Steptoe, Sutcliffe, Allen and Coombes (1991) concluded that cancer patients who used information-seeking to cope with stress were not necessarily less anxious than those who used avoidance coping. On the other hand, some studies with cancer patients reported positive effects of information on reducing anxiety, improving knowledge of disease, and enhancing sense of meaning in life (Johnson, 1982; Cohen, Sullivan, & Branechog, 1988).

Several studies suggested that the most effective approach was a combination of informational and emotional support. Weisman (1979) claimed that persons with cancer seemed to adjust better emotionally when they were given ample information, conveyed with compassion and candour. Follick, Smith and Turk (1984) noted that higher levels of information and social support were significantly correlated with better emotional and social adjustment in persons who had ostomies for cancer. In studies exploring the effect of communication on cancer patients' coping and adjustment, Roberts, Cox, Reintgen, Baile and Gibertini (1994), and Steptoe et al. (1991) concluded that information provision was valued largely within the context of a compassionate and caring relationship.

Dunkel-Schetter (1984) examined perceptions of the effectiveness of various types of support in a sample of 79

patients with breast or colo-rectal malignancies. Data were collected through tape-recorded semi-structured interviews. Emotional support emerged as one of the most helpful behaviours (81%), while informational support was also important (41%). Support was shown to have a significantly positive association with adjustment, except for those with a poor prognosis. Health professionals were seen as a key group in the social support process.

A number of authors explored the role of health professionals and the process of cancer patient education. Rimer, Keintz and Glassman (1985) conducted a thorough review of the literature on cancer patient education, and concluded that in spite of the apparent importance of providing information, little attention had been paid to cancer education. They suggested, at that time, that the agenda for the future should include increasing effort devoted to cancer patient education. Grahn and Johnson (1990) investigated the learning needs of persons with cancer. They suggested that patients were not using staff members as a resource to gain needed information and that the learning needs were not being met by the present system of providing information. Adams (1991) and Fredette (1990) emphasized the changing nature of the cancer experience and proposed that patient education models should reflect the phases of the cancer experience.

Head and Neck Cancer

Cancer of the head and neck includes tumours of the upper aerodigestive tract and salivary glands, as well as tumours of the skin, soft tissue, bone, and neurovascular structures of the head and neck (Norris & Cady, 1991; Shah & Lydiatt, 1995). This type of cancer accounts for about 6% of all malignancies (Yuska Bildstein, 1993). It is more prevalent after the age of 50, (Cachin, 1989), and is more common in men than women, although the incidence in women is increasing. The largest contributing factor to the development of head and neck cancer is chronic irritation to the structures of the head and neck, particularly from longterm use of tobacco and alcohol (Cachin, 1989).

The physical and psychosocial factors are often inextricably linked. Head and neck cancer frequently occurs in persons who exhibit premorbid characteristics of dependence, inability to change habits, and poor coping skills (Bolund, 1985; Breitbart & Holland, 1988; Dropkin, 1989).

The Psychosocial Impact of Head and Neck Cancer

Most studies that explored the psychosocial impact of head and neck cancer focused on a specific aspect of the disease or its treatment. Several researchers investigated adjustment after surgery for head and neck cancer.

Dropkin and Scott (1983) examined body image reintegration and coping effectiveness after head and neck surgery in a sample of 38 men and 14 women. Data were collected in the early postoperative period using the Social Desirability Scale and the Disfigurement/Dysfunction (D/D) Scale, developed by the researchers. Findings indicated that self-care and social affiliation were the primary behavioral manifestations of the coping process. Dysfunction appeared to be more readily incorporated than disfigurement. The authors suggested that coping capacity may be diagnosed from observable behaviour in the early postoperative period. They asserted that the study findings could be used to guide care planning and facilitate achievement of expected outcomes.

The impact of surgery on head and neck cancer patients' pain, fatigue, and mood over time was explored by Watt-Watson and Graydon (1995). Their convenience sample consisted of 44 patients and their caregivers. Patients were interviewed on admission, prior to discharge from the hospital, and four weeks after discharge. The Brief Pain Inventory and the Profile Of Mood States were used for data collection and qualitative concerns were also assessed. The researchers found that anxiety was the most prevalent mood at all interviews, but it gradually decreased over time. The authors noted that patients experienced considerable

disruption in their usual routines, especially socializing, and returning to work was problematic for some. Before and after surgery, patients asked for more information about their prognosis, activity, and continued care. As suggested by Watt-Watson and Graydon, further research is needed to assess concerns of patients and caregivers at various stages of treatment and how best to support them through the process.

Gamba et al. (1992) explored the long term effects of disfigurement on psychosocial adjustment to head and neck cancer. Their sample consisted of 66 patients, from six months to eight years after surgery. Subjects were divided into two groups based on the degree of disfigurement (minor or severe). Psychosocial data were collected through a structured interview and open-ended questions. Assessment areas included self-image, relationships with partner, children and friends, and overall impact of surgery. The findings showed that the amount of distress was linked to the tumour site and the type of surgery performed. Persons with lesser disfigurement were able to satisfactorily overcome cancer and adjust to their changed appearance, but psychosocial adjustment in persons with extensive disfigurement did not seem to improve with time. The authors asserted that greater attention should be paid to the psychologic consequences of head and neck cancer. They

suggested that it may be useful to study patient's self-concept as an indicator of risk for psychosocial maladjustment.

Olsen et al. (1995) conducted a related study to explore quality of life after surgical treatment for cancer of the larynx. The sample of 111 patients was divided into three groups based on whether they had a total, near-total, or partial laryngectomy. Most patients were from 12 to 48 months post-surgery. Data were collected using the Psychosocial Adjustment to Illness Scale (PAIS) and the Mayo Clinic Postlaryngectomy Questionnaire (MCPLQ). The authors noted that the partial laryngectomy group reported better psychosocial adjustment in all domains than the other two groups. With only a few exceptions, the adjustment of the laryngectomy patients was slightly less favourable than a comparison mixed cancer group. Less than half of the patients thought they were adequately educated about the changes the operation would cause in their lives. The newly developed MCPLQ was tested, however, the PAIS appeared to reflect the patients' feelings more accurately. The authors emphasized the need for further investigation and standardization of measurement tools.

Bunston and Mings (1994) undertook a two phase study to develop and test an instrument to assess symptom management and psychosocial needs of persons with head and neck cancer.

Data needed to develop the Needs Assessment Inventory was gathered in the initial qualitative phase. The subsequent quantitative phase tested the instrument in a sample of 98 outpatients with head and neck cancer, with an average length of time since diagnosis of two years. Data were then collected using the Needs Assessment Inventory and several other established instruments to assess hope, mood, psychological well-being and quality of life. The findings indicated that patients had multiple and interrelated needs. Almost half of the sample expressed unresolved needs and identified lack of information as one of the barriers to needs resolution. A number of revisions were made to the tool based on the findings, however, the authors concluded that it was a valid and reliable approach to needs assessment.

The only study located that examined psychosocial adjustment at different points in time in persons with head and neck cancer was conducted by Rapoport et al. (1993). Their sample consisted of 55 patients, divided into three groups based on the time since diagnosis: 14 short-term (six to 18 months), 28 medium term (19 months to five years), and 13 long term (more than five years). Data were collected using the researcher-developed Patient Adjustment Questionnaire, that assessed psychosocial adjustment in 14 domains. From the results, the researchers concluded that

persons with head and neck cancer suffered from a broad range of problems. While many medical problems decreased, most psychosocial problems exacerbated over time. The authors asserted that psychological deterioration could be decreased by teaching adequate coping skills.

Information Needs and Head and Neck Cancer

Only one study was found that investigated the specific information needs of persons with head and neck cancer. Glavassevich et al. (1995) conducted a retrospective study in a convenience sample of 32 post-surgical patients. Using a researcher-developed questionnaire, patients identified what information was given, by whom, when, and what information they found most and least helpful. Patients also indicated what symptoms they had experienced before and after surgery. Respondents reported that the nature and extent of surgery were well explained, however, most stated that they were not adequately prepared for some of the outcomes they experienced after surgery. They identified that the latter information was most helpful and necessary to know. All respondents reported that they received information from their physician and 10 (30%) also received information from the nursing staff. The findings showed that fear and anxiety were the most frequently experienced symptoms before surgery, while physical symptoms were more prevalent after surgery. The authors contended that

anxieties could be reduced through provision of information to patients. They suggested formalizing teaching content and tailoring information to individual needs and learning styles.

Informational Support and Adjustment to Head and Neck Cancer

A computer search and use of reference lists failed to reveal any studies that specifically explored the relationship between informational support and adjustment to illness, of any kind. A few authors alluded to these variables within other studies or in published conceptual literature. The following review will address the most pertinent information extracted from available reference sources related specifically to head and neck cancer.

Pruyn et al. (1986) conducted a comprehensive review of the literature on the psychosocial aspects of head and neck cancer. They concluded that patients with head and neck cancer experienced a variety of psychosocial problems and were in great need of information about their illness and treatment. The authors proposed that professionals could play an important role in providing information and support. Information and support were related to a decrease in depression, improvement in social functioning, and positive rehabilitation outcomes. Similar conclusions were made by Mathieson, Stam and Scott (1990) following their review of the literature on adjustment after laryngectomy. They

asserted that positive outcomes of information and support included shorter hospital stays, lower levels of reported pain and less use of analgesics postoperatively. Koster and Bergsma (1990) reviewed the literature on the problems and coping behaviours of patients with facial cancer and concluded that providing information, guidance and support may be preconditions to successful recovery.

Dropkin and Scott (1983) explored coping effectiveness following surgical treatment for head and neck cancer. They emphasized the importance of interactions with staff and teaching of new tasks to facilitate learning and assist in the reintegration process. Other studies by Watt-Watson and Graydon (1995) and Glavassevich et al. (1995) suggested that a formalized teaching program could reduce anxiety experienced by patients with head and neck cancer.

Summary of Literature

A diagnosis of cancer raises anxieties and fears about the future, and poses a serious threat to one's psychosocial integrity. Head and neck cancer has been described as one of the most emotionally traumatic types of cancer. Persons with head and neck cancer experience a variety of psychosocial problems, that may continue for many years following the cancer diagnosis. The course of cancer has been characterized by a series of phases, each with its unique vulnerabilities and coping challenges. Although the

majority of persons adapt to the changes imposed by cancer, adjustment requires considerable coping effort.

Information-seeking has been identified as a primary coping mode used to deal with a stressful event such as cancer. Studies have indicated that most individuals with cancer want to be well informed. However, providing information to persons with cancer has been largely based on what nurses feel is important, rather than on patients' perceived needs.

Although it is generally acknowledged that information helps persons cope with stress and adjust to illness, there were very few published studies that investigated the relationship between informational support and psychosocial adjustment in persons with cancer.

There were several notable gaps and weaknesses in the research investigating information needs of persons with cancer. This was especially true in relation to head and neck cancer. Most studies focused on the initial phase of the cancer experience. The sample for several studies included persons with cancers of diverse sites and at various disease phases. No studies were found that explored changing information needs at different phases along the cancer continuum. Luker et al. (1995) noted, however, that a longitudinal follow-up study was underway. As stated by Lazarus (1993), "To collapse what is happening over time is

apt to produce findings that are at best uninterpretable and at worst misleading" (p. 239). New instruments, without known reliability and validity, were used to answer the specific research questions of most studies and some of the procedures for data collection were very time consuming.

In the past year, several studies have been published exploring the psychosocial effects of head and neck cancer, especially in patients treated surgically. However, no studies have focused on different phases of the cancer experience, and there has been limited exploration of the role and effect of various interventions, including information-giving, in facilitating adjustment.

This study, therefore, was designed to yield data to address identified gaps in the literature and provide nurses with information to guide practice. In particular, the study would investigate perceived information needs and psychosocial adjustment in persons with head and neck cancer, at three different phases of the cancer experience. The study would also explore whether a correlation could be shown between the quality of informational support received and psychosocial adjustment to head and neck cancer.

Conceptual Framework

Lazarus and Folkman's (1984) theory of stress, appraisal and coping was chosen as the conceptual framework for this study. Selected elements of this theory, that have

relevance to the research questions, were used to guide the theoretical approach in this project.

Lazarus and Folkman postulated that the way individuals appraise an event, such as illness, and how they use available internal and external coping resources, strongly affects how they react emotionally and how they adjust to changes imposed by the event.

Stress is defined as "a particular relationship between the person and the environment, appraised by the person as taxing or exceeding one's resources and endangering well-being" (p. 19). People differ in their sensitivity and vulnerability to certain situations. Based on their past experiences, coping abilities and the meaning of the event for them, individuals may appraise a situation differently. Environmental factors may also differ and include the novelty, predictability and uncertainty of an event, the imminence and duration of an event, and the ambiguity or lack of situational clarity of an event.

Cognitive appraisal processes mediate one's reactions to an event perceived as stressful, and are essential for adequate psychological understanding. Lazarus and Folkman identified phases of cognitive appraisal. Primary appraisal refers to the evaluation of the significance of an event for one's well being. An event may be appraised as a harm/loss, damage that has already occurred; a threat, anticipated or

future harm; or a challenge, a situation to be mastered that could result in personal growth or gain. Secondary appraisal refers to a judgement about what might or could be done to deal with the situation. It takes into account what coping options are available, whether a given coping strategy will accomplish the task, and whether the person can effectively apply the strategy. Primary and secondary appraisal interact to shape the degree of stress and to influence coping.

Coping refers to the constantly changing cognitive and behavioral efforts used to manage or alter the event causing the stress (problem-focused coping), and to regulate the emotional responses to the problem (emotion-focused coping). Effective coping depends on the availability of internal resources, such as energy, positive beliefs, and problem solving skills; and external resources, such as information, social support, and material resources. What a person does to cope varies with the context of the situation. Lazarus and Folkman suggested that information seeking is one of the most basic coping modes, and the first to be used when confronted with a new or uncertain situation.

The stress, appraisal and coping theory of Lazarus and Folkman and the earlier stress and coping theory of Cohen and Lazarus (1979) have been used by several researchers

investigating aspects of information seeking or adjustment in persons with cancer.

Derdiarian (1987a, 1987b) and Davison et al. (1995) used the theory to guide the investigation of the information needs of persons newly diagnosed with cancer. Findings of both studies provided support for Lazarus and Folkman's postulation that the relevance of information needed by patients is related to the imminence of perceived threats or harms associated with an illness.

Dropkin and Scott (1983) and Koster and Bergsma (1990) used Lazarus and Folkman's theory as the framework in their studies of coping in persons with head and neck cancer. Their findings supported the postulation that coping is a highly complex, multidimensional process that changes over time.

All of the above studies provided support for Lazarus and Folkman's theory. In a study exploring the relationship between information-seeking and adaptational outcomes in women receiving chemotherapy for breast cancer, Brolin-Hopkins (1986) concluded that the theory was not helpful in predicting adaptive outcomes. However, the theory helped explain the stressful sequence of events and the patients' coping responses associated with cancer chemotherapy.

Relevance of Framework to the Proposed Study

Head and neck cancer constitutes an event, that is usually characterized by novelty, ambiguity, and uncertainty that may persist for an extended period of time. Persons with head and neck cancer have been identified as a psychologically vulnerable group, because of both person and disease-related factors. How they appraise and manage the demands of their disease and its treatment will affect their adaptational outcomes. Information-seeking is one coping mode used by individuals to manage a stressful event. In keeping with Lazarus and Folkman's theory, the researcher believed that the more effectively the information needs of persons with head and neck cancer are identified and met, the better they will be able to reappraise and manage their situation. Access to needed information would help them cope and adjust more positively to changes imposed by their illness. This was the theoretical rationale for the study.

Definition of Terms

The following terms were used in the study:

Information need: Any type of information identified as needed or wanted by the individual because of changes or problems resulting from head and neck cancer.

Informational support: The provision of information, advice, suggestion, or feedback about how one is doing.

Quality of informational support received: The individual's perceived satisfaction with informational support provided. For this study it included how adequately information needs were met, and the manner in which information was provided.

Psychosocial adjustment: A dynamic and multidimensional concept that relates to the process whereby an individual's equilibrium is re-established to its pre-illness state or a new state, which may be either higher or lower than its previous state. For this study adjustment included role function, relationships with family and friends, emotional well-being, and self-concept.

Person with head and neck cancer: A person whose primary cancer involved the head and neck region, excluding the brain, spinal cord and thyroid gland.

Extent of disease at diagnosis: The extent of disease at diagnosis as reported in the pathology reports and surgical records.

> localized - the tumour was confined to the primary site with no evidence of invasion into surrounding tissue.
>
> regional extension - the tumour had invaded the surrounding tissue but extension was limited and was confined to the nearby area.

massive tumour - the tumour had extensively involved the surrounding tissue but there was no evidence of lymph node involvement.

node involvement - there was evidence of lymph node involvement in the area around the tumour site.

distant metastasis - the tumour had spread beyond the regional area to other body site(s).

Disfigurement: Disruption to the physical structures of the head and neck.

Dysfunction: Disruption to the physical functions of the head and neck.

Amount of disfigurement/dysfunction: A measure of the extent of disfigurement/dysfunction, assessed by direct observation, review of the medical record, and/or perceptions communicated to the researcher by the participant. The criteria were:

minimal - slight visible disfigurement and/or minor reported dysfunction, such as with speech, swallowing.

moderate - more obvious disfigurement, such as tracheotomy, facial reconstruction, bilateral neck dissection, or dysfunction such as loss of speech or inability to take food orally.

severe - extensive visible disfigurement along with loss of function, such as speech, eating, sight.

CHAPTER III

Method

Research Design

This study used a retrospective, descriptive correlational, cross-sectional design. The design was selected because it was felt to be an appropriate and practical approach to answer the research questions. Although a longitudinal design conducted over time with the same individuals might be a better approach, this was not considered practical because of the time constraints.

Sample

A purposive convenience sample was used. The sample included persons with head and neck cancer at three different phases of the cancer experience. The time periods selected for this study reflected Mullan's (1985) three seasons of survival.

The sample was subdivided as follows:

Group A: (acute survival) - persons within three months of diagnosis,

Group B: (extended survival) - persons within three months of completion of treatment,

Group C: (permanent survival) - persons 12 to 24 months following diagnosis.

For this study, recurrence was considered similar to a new diagnosis. Although cancer may recur more than a year

after the initial diagnosis, the psychological responses and information needs are more reflective of the phase of new diagnosis than of continuing care (Adams, 1991; Mahon, Cella, & Donovan, 1990; Weisman, 1979).

Eligibility Criteria

To be included in the study the person had to:

1. have a definite diagnosis of head and neck cancer.
2. have been informed of the diagnosis.
3. be 18 years of age or over.
4. fall into one of the three subgroups identified for the study.
5. be able to understand and respond to the questionnaire.

Patients were not asked to participate if they appeared to be visibly upset because of circumstances related to their clinic visit. It was felt that partaking in the study at this time was not a priority. Because their care was continued through the agencies used for this study, they could have been approached at a later, more suitable date.

Of the 73 eligible participants, 65 consented to take part in the study (11% refusal rate). Some of the reasons given for refusal included a lack of interest in the study, having inadequate time to complete the questionnaire, or feeling too unwell to participate. The final sample consisted of 20 participants in Group A, 20 in Group B, and 25 in Group C. Most participants were accessed through the

local cancer centre, which is the referral site for persons with cancer throughout the province. Two participants were accessed through a local hospital.

Setting

The questionnaire was completed in a private room in the cancer centre or in the privacy of the patient's hospital room. Distractions were minimized during completion of the questionnaire.

Instrument

A variety of instruments designed to assess aspects of information, psychosocial adjustment and quality of life were reviewed. Although many had merits, they did not capture the issues addressed in this study, and/or were long and complex. Several instruments assessed information needs of persons with cancer, however, most were designed for specific populations. Numerous instruments assessed psychosocial status and/or coping, but they did not address the specific research questions outlined for this study.

Two instruments were more critically reviewed for possible use in this study. One was the Needs Assessment Survey used by the Canadian Cancer Society (1992). It was the only instrument that included both information needs and psychosocial adjustment. The tool was comprehensive and included relevant assessment items, however, it was very long, assessed all areas of need (not just information), and

required administration by the researcher or a trained assistant. The second instrument was the Psychosocial Adjustment to Illness Scale - Self Report (PAIS-SR) developed by Derogatis (1978), which has been quite extensively used for persons with cancer. The assessment domains and items were appropriate, however, the readability level was high, and many items were lengthy and complex.

Following the extensive review of instruments, the researcher concluded that none of the previously used and validated instruments would be suitable for this study and/or the target population. Subsequently, a new tool was developed. It was recognized that there are weaknesses inherent in this approach, however, it was felt that the advantages outweighed the disadvantages.

The Questionnaire

The questionnaire developed for this study (Appendix A) incorporated ideas garnered from the literature and the instrument review and was designed to answer the research questions. Most items obtained quantitative information, using a six point Likert-type rating scale. One open-ended question was included to allow participants the freedom to express ideas that were not captured by the structured questions. The questionnaire was designed to be self-administered, with researcher assistance, as needed. In anticipation of an older age group, with less than perfect

eyesight, the print size and lay-out of the questionnaire were given special attention.

The questionnaire consisted of eight sections:

Section 1 included basic demographic information. It focused on factors identified in the literature as being most relevant to the study population and/or the variables under investigation.

Section 2 explored participants' information needs during the past 30 days. Participants were asked to rate how important it was for them to receive information in 19 identified areas, on a scale that ranged from 0 (does not apply) to 6 (very important). Information items were based on a review of the literature and other studies (Canadian Cancer Society, 1992; Cassileth et al., 1980; Derdiarian, 1987a, 1987b).

Section 3 consisted of three subsections. The first subsection asked participants to rate how much information they had received to meet their own needs in each of the areas identified in Section 2. Responses ranged from 0 (does not apply) to 6 (all I wanted or needed). The second subsection asked participants to rate how they felt about the way that information was provided. It included items such as the sensitivity of the information providers, clarity of information, encouragement to ask questions, and helpfulness of answers to questions (see Appendix A).

Options ranged from 1 (not very) to 6 (very much). The third subsection asked what group(s) of individuals were most helpful in providing information. Participants could identify up to three groups.

Section 4 examined participation and information preferences, as a component of information need.

Section 5 sought participants' opinions about the helpfulness of various methods of providing information, using a scale that ranged from 1 (not helpful) to 6 (very helpful). This item was included to provide information for future program planning, but the data were not analyzed as part of this study.

Section 6 examined participants' psychosocial adjustment since their cancer diagnosis. It included four subsections: role adjustment, emotional responses, feelings about self, and overall functioning. Role domains included personal roles, vocational roles, relationship with partner, relationship with other family members, relationship with friends, and social/leisure activities. Statements were provided and participants were asked to rate how true they were on a scale from 1 (very untrue) to 6 (very true).

Section 7 consisted of an open-ended question asking participants if they would like to add anything else that they felt would be helpful in meeting the needs of persons with cancer like themselves.

Section 8 included basic medical information relevant to head and neck cancer and its treatment. This section was completed by the researcher. Information was obtained from the medical record.

The instrument was reviewed by three knowledgeable colleagues to establish comprehensiveness and content validity prior to its use in this study. The questionnaire was then pilot tested with six participants, who met the selection criteria. The pilot test indicated that approximately 20 minutes were needed to self-administer the questionnaire. Slightly longer time was needed if the researcher had to assist the participant. Participants were asked to comment on clarity and ease of responding to the questions. As only a few minor changes were made after the pilot test, to increase clarity and simplicity of some items, these participants were included in the final sample.

Internal consistency of the questionnaire was assessed using Cronbach's alpha (n = 65). Reliability analysis was computed for each of the subsections and the two major sections of the instrument. Alpha values for the subsections were: information needs .94; ways of providing information .75; informational support .90; satisfaction with information received .95; roles and relationships .89; emotional responses .83; feelings about self .83; and overall functioning .71. The two major sections of the

instrument (Information Needs and Support, and Psychosocial Adjustment) were analyzed separately because they were essentially two different instruments included in the same questionnaire. Alpha values for both sections were .91.

These were all high reliability coefficients. According to Nunnally (1978), a reliability of .80 is suitable for instruments used in basic research (p. 245).

Ethical Considerations

Following approval of the Human Investigation Committee of Memorial University of Newfoundland and the Medical Advisory and Ethics Committees of the relevant agencies (Appendix B), the researcher briefed the physicians and nurses who worked with the study population and whose assistance would be required. The study was explained, they were given written information (Appendix C), and their assistance was solicited and obtained.

The privacy and confidentiality of the participants were assured. Participants were also informed that they could refuse to answer any question and could change their mind about participating at any time. Code numbers, not names, were used on all questionnaires. Completed questionnaires and the master list of names and code numbers were kept under lock and key and were accessible only to the researcher.

Procedure

Data were collected from May, 1995 to November, 1995. Suitable participants were identified by the nurses, doctors or radiation therapists working in the study settings. They provided patients with an introductory explanation about the study (Appendix D), and obtained their verbal agreement to meet with the researcher for further discussion. Those who agreed, were introduced to the researcher. In the private research setting, the details of the study were explained (Appendix E) and the patient's written consent to participate was obtained (Appendix F). The researcher left the room and the patient completed the questionnaire on his/her own, if able. The participant was informed that the researcher would remain nearby and would periodically check to answer any questions and assist if needed. Several participants required help and the researcher remained with them and administered the questionnaire. Following completion of the questionnaire, the researcher obtained medical information through a chart review. The questionnaire was administered only once to each participant.

Data Analysis

The Statistical Package for the Social Sciences - SPSS for Windows (Norusis, 1993) was used for all data analysis procedures.

Descriptive statistics were used to address the first three research questions. Frequency distributions and mean values were obtained for each questionnaire item. The scores for two items (Appendix A, Questionnaire #20. f. and g.) were reversed so that all high scores would reflect positive responses. Overall mean scores for the total sample and each subgroup were computed for each subsection of the questionnaire.

Inferential statistics, employing *Spearman's rho*, were used to explore the relationship between informational support and psychosocial adjustment. This statistic was selected because the data were skewed to mostly 5 or 6, which were not normally distributed. The test is also suitable for ordinal data (May, Masson, & Hunter, 1990; Polit & Hungler, 1995).

Individual composite mean scores were calculated for perceived quality of informational support received and psychosocial adjustment. To calculate the mean value for informational support, the scores for all items in Section 3 (Appendix A, Questionnaire #9 and #10) were summed. An overall individual mean score, as well as mean scores for each item in Section 3 were derived. To calculate the mean value for psychosocial adjustment, a composite score that included roles and relationships, emotional responses, and feelings about self was obtained. The scores for all items

in Section 6 (Appendix A, Questionnaire #'s 14-21) were summed and an overall individual mean score was derived. The *Kruskall-Wallis* one-way analysis of variance was used to measure any significant difference of mean scores among the three subgroups. This nonparametric test is suitable for comparing the means of two or more groups when the variable is measured on an ordinal scale. The *Mann-Whitney U* nonparametric test was then used to further measure any significant difference of mean scores between pairs of subgroups (May et al., 1990; Polit & Hungler, 1995). The difference was considered significant when the p level was $\leq .05$.

All qualitative data from the questionnaires were transcribed verbatim. Qualitative data that related to the research questions were analyzed. Analysis began with a search for themes and identification of categories. Data were coded into relevant categories (Polit & Hungler, 1995; Skodol Wilson, 1989). Where possible, categories were organized to reflect the research objectives. A knowledgeable colleague was asked to review the raw and categorized data to validate the derived categories.

Summary of Methods

Several measures were taken to improve the validity of this study. A cross-sectional design was used to identify and compare the study variables in three subgroups of

persons with head and neck cancer, at key periods during the cancer experience. Mullan's (1985) "seasons of survival" were selected as the time periods because they depict changing phases of the cancer continuum, when persons encounter new challenges and experience new vulnerabilities.

The instrument was designed to incorporate important elements gleaned from the literature, and reflect the conceptual framework used for this study. Readability, clarity and conformity of format were also considered in instrument composition. Rating scales and structured questions were used to obtain different types of data. One open-ended question was included to capture additional information. Reliability tests done after completion of the study indicated high alpha values for all sections of the questionnaire (.71-.94).

Before implementing the study, the researcher met with the health care providers whose cooperation would be needed, and oriented them to the study. During completion of the questionnaire participants were made to feel relaxed, in a comfortable, private setting.

A total sample size of 65 was considered adequate for statistical procedures. Descriptive and inferential statistics, employing nonparametric tests, were used in data analysis. The difference among means was considered significant if $p \leq .05$.

CHAPTER IV

Results

Characteristics of the Sample

Demographic Characteristics

The subgroups were comparable on all measured demographic characteristics except for age and education. Group A had a larger proportion of older persons, and Group C had a larger proportion of persons with higher education. Most participants were male (86%), over 50 years of age (74%), married and living with their spouse (89%). The majority had less than ten years of education (58%) and were retired or not working (66%) (Table 1).

Participants represented all areas of Newfoundland. One participant, with a good command of English, came from St. Pierre (Table 2). The local cancer centre is the referral site for patients from this French island which is approximately 40 kilometres from Newfoundland.

Medical Characteristics

Most participants had cancer of the throat or oral cavity (68%), however, all other head and neck sites were represented in the sample. This was the initial diagnosis for 82% of the participants and 72% had more than localized disease at the time of diagnosis, but none had distant metastasis. Most participants were treated with surgery (60%) and/or radiotherapy (85%)(Table 3). Eighteen per cent had more than minimal disfigurement/dysfunction (Table 4).

Table 1

Demographic Characteristics of Sample (N = 65)

Characteristic	Group A n = 20	Group B n = 20	Group C n = 25	All (%) n =65
Gender				
Male	17	16	23	56 (86.1)
Female	3	4	2	9 (13.8)
Age Group				
16-24 yrs.	0	0	1	1 (1.5)
25-34 yrs.	0	1	0	1 (1.5)
35-49 yrs.	2	6	7	15 (23.1)
50-64 yrs.	6	6	8	20 (30.8)
65-79 yrs.	12	4	7	23 (35.4)
80 + yrs.	0	3	2	5 (7.8)
Marital Status				
Married/Common Law	18	18	22	58 (89.2)
Divorced/Separated	0	1	1	2 (3.1)
Widowed	1	1	1	3 (4.6)
Single	1	0	1	2 (3.1)
Live With				
Spouse alone	-	-	-	40 (61.5)
Spouse & other	-	-	-	18 (27.7)
Other	-	-	-	7 (10.8)
Education in Yrs.				
0-3	3	1	1	5 (7.7)
4-6	5	2	3	10 (15.4)
7-9	8	9	6	23 (35.4)
10-12	3	7	12	22 (33.8)
13-15	1	0	0	1 (1.5)
16-18	0	1	2	3 (4.6)
19+	0	0	1	1 (1.5)
Employment				
Full Time	1	2	5	8 (12.3)
Part Time	2	1	0	3 (4.6)
Homemaker	1	2	0	3 (4.6)
Retired	12	7	13	32 (49.2)
Seasonal	0	3	4	7 (10.8)
Not Working	4	5	2	11 (16.9)

Table 2

Geographical Distribution of Sample (N = 65)

Region	% of Sample	Region	% of Sample
Avalon	27.7	Central	12.3
St. John's	24.6	Western	9.2
Eastern	16.9	Labrador	7.7
		St. Pierre	1.5

Table 3

Medical Characteristics of Sample (N = 65)

Information	Group A n = 20	Group B n = 20	Group C n = 25	All (%) n = 65
Diagnosis by site				
Throat	8	6	11	25 (38.5)
Nasopharynx	3	2	3	8 (12.3)
Salivary glands	2	1	1	4 (6.1)
Mouth	6	7	6	19 (29.2)
Skin	0	3	4	7 (10.8)
Other	1	1	0	2 (3.1)
Disease Status				
Initial disease	18	15	20	53 (81.5)
Recurrence	2	5	5	12 (18.5)
Extent of disease at Diagnosis				
Localized	7	4	7	18 (27.7)
Regional extension	5	3	8	16 (24.6)
Extensive tumour	3	2	2	7 (10.8)
Node involvement	5	11	8	24 (36.9)
Distant metastasis	0	0	0	0
Treatments (past or present)				
Surgery	11	11	17	39 (60.0)
Radiotherapy	15	18	22	55 (84.6)
Chemotherapy	1	3	5	9 (13.8)

Table 4

Amount of Disfigurement/Dysfunction (N = 65)

Disfigurement/ Dysfunction	Group A n = 20	Group B n = 20	Group C n = 25	All (%) n = 65
None	7	5	6	18 (27.7)
Minimal	10	12	13	35 (53.8)
Moderate	3	3	5	11 (16.9)
Severe	0	0	1	1 (1.5)

Information Needs

Research Question #1. What are the information needs of persons with head and neck cancer: a) following diagnosis, b) following treatment, and c) during rehabilitation/continuing care?

Importance of Information

To assess information needs, participants were asked to rate how important each of 19 identified information items was in the 30 days prior to the interview. No participant added any new item under the category "other". The mean importance scores for most items decreased, the further the subgroup was from diagnosis (Table 5).

Table 5

Mean Scores for Information Needs (N = 65)

Information Item	Group A n = 20	Group B n = 20	Group C n = 25	All n = 65
Your medical condition	5.8	5.7	4.5	5.2
Treatment choices	5.7	4.1	2.6	4.0
Your treatment(s)	6.0	4.0	2.7	4.0
Possible side effects	5.8	4.6	2.9	4.3
Possible outcomes	5.8	4.6	2.9	4.3
Possible emotional reactions	5.0	4.4	2.9	4.0
How to relieve discomfort	5.9	4.7	3.2	4.5
How to cope with changes	5.0	4.2	3.0	4.0
Diet and Nutrition	5.5	4.5	3.0	4.2
Possible effects on sex life	3.2	2.8	2.1	2.6
Possible effects on soc. life	3.1	3.6	2.2	2.9
Possible effects on work life	3.0	3.6	2.3	2.9
Self-care measures	4.3	4.0	2.4	3.5
Home care services	3.0	2.7	2.0	2.5
Emotional support/Counselling	3.2	2.8	2.2	2.7
Spiritual support	3.4	3.9	2.8	3.3
Meet others with cancer	3.8	3.3	2.7	3.2
Get equipment/supplies	1.9	3.7	2.2	2.6
Financial support	3.0	3.9	2.0	2.9
Overall Needs Score	4.3	4.0	2.7	3.6

Note. Scale = 1 (Not important) to 6 (Very important)

For easier viewing, information items for each group were categorized into high (scored 5-6), medium (scored 3-4) and low (scored 1-2) priority needs and then rank ordered. Of note, Group C, who were 12 to 24 months since diagnosis, did not identify any item as very important (Table 6).

Table 6

Priority of Information Needs (N = 65)

A. High Priority (5-6)	Rank	Mean
Group A (n = 20)		
How to relieve discomfort	1	5.9
Your Treatment(s)	2	5.8
Your medical condition	2	5.8
Possible side effects	2	5.8
Possible outcomes	2	5.8
Treatment choices	3	5.7
Diet and nutrition	4	5.5
Possible emotional reactions	5	5.0
How to cope with changes	5	5.0
Group B (n = 20)		
Your medical condition	1	5.7
Group C (n = 25)		
(None)		

Note. Scale = 1 (Not important) to 6 (Very important)

(continued)

Table 6 (cont.)

B. Medium Priority (3-4)	Rank	Mean
Group A (n = 20)		
Self-care measures	6	4.3
How to meet others with cancer	7	3.8
Spiritual support	8	3.4
Possible effects on sex life	9	3.2
Emotional support/counselling	9	3.2
Possible effects on social life	10	3.1
Possible effects on work life	11	3.0
Home care services	11	3.0
Financial support	11	3.0
Group B (n = 20)		
How to relieve discomfort	2	4.7
Possible side effects	3	4.6
Possible outcomes	3	4.6
Diet and nutrition	4	4.5
Possible emotional reactions	5	4.4
How to cope with changes	6	4.2
Treatment choices	7	4.1
Your treatment	8	4.0
Self-care measures	8	4.0
Spiritual support	9	3.9
Financial support	9	3.9
Get equipment/supplies	10	3.7
Possible effects on social life	11	3.6
Possible effects on work life	11	3.6
How to meet others with cancer	12	3.3
Group C (n = 25)		
Your medical condition	1	4.5
How to relieve discomfort	2	3.2
How to cope with changes	3	3.0
Diet and nutrition	3	3.0

Note. Scale = 1 (Not important) to 6 (Very important)

(continued)

Table 6 (cont.)

C. Low Priority (1-2)	Rank	Mean
Group A (n = 20)		
Get equipment/supplies	12	1.9
Group B (n = 20)		
Possible effects on sex life	13	2.8
Emotional support/counselling	13	2.8
Home care services	14	2.7
Group C (n = 25)		
Possible side effects	4	2.9
Possible outcomes	4	2.9
Possible emotional reactions	4	2.9
Spiritual support	5	2.8
Your treatments	6	2.7
How to meet others with cancer	6	2.7
Treatment choices	7	2.6
Self-care measures	8	2.4
Possible effects on work life	9	2.3
Possible effects on social life	10	2.2
Emotional support/counselling	10	2.2
Get equipment/supplies	10	2.2
Possible effects on sex life	11	2.1
Home care services	12	2.0
Financial support	12	2.0

Note. Scale = 1 (Not important) to 6 (Very important)

Priorities differed among the three subgroups. For Group A, disease and treatment items ranked highest. For Groups B and C, items related to treatment ranked lower, while items relating to the disease and coping with side effects were primary concerns, though only rated of moderate importance.

The *Kruskall-Wallis* test indicated that the importance of information needs between the three subgroups differed significantly ($p = .0005$). Further analysis, using the *Mann-Whitney U* test, revealed that the difference was not significant between Groups A and B ($p = .199$), but was significant between Groups A and C ($p = .0003$), and between Groups B and C ($p = .007$).

Some of the qualitative data from the open-ended question identified information needs and expanded on the quantitative data. There were too few comments to identify recurring themes. One comment suggested a need for more information to decrease anxiety on the first visit to the cancer centre.

> "Perhaps more information about the Cancer Centre before you first visit...eg. what to expect in terms of environment, nurses, etc. Fear of the unknown makes you more nervous."

Other comments identified a need for more information regarding medical care and treatment issues.

> "In the early stages of hospitalization, I would have appreciated more explanations about why test results are slow and would have liked more contact with my doctor."

> "Although it is difficult to predict how much treatment each person will get and how it will affect them, I suggest more effort should be put into explaining to people the effect of the treatment and the recovery period.'

Two comments reflected special needs of participants. They expressed concern that their special needs were not given adequate consideration.

> "When you can't see, things can be confusing. Most people take it for granted that if you don't wear glasses, you can see. This also applies if you are hearing impaired." (from a blind lady)

> "Because we are French speaking, the family needs to be told more. We need a contact person, one is not enough. This is especially true regarding emotional support issues. You are given medical and treatment information, but the patient and family need more about how to deal with it. There should be French information available in Montreal."

The cancer centre and the adjoining hospital share one part-time liaison nurse who coordinates french language services for the people from St. Pierre and helps with translation. This is a relatively new service and is still in the developmental stages.

Information and Participation Preferences

Most participants (75%), across all subgroups, wanted as much information as possible. Slightly over half (54%) of all participants preferred to leave decisions about medical care to the doctor. Preference for active involvement in decision-making increased as the time from diagnosis lengthened. Fifty-six per cent of participants in Group C preferred to participate in the decision-making process compared to only 30% in Group A (Table 7).

Table 7

Information and Participation Preferences (N = 65)

Preference	Group A n = 20	Group B n = 20	Group C n = 25	All (%) n = 65
Information				
I want only the information needed to care for myself properly	2	4	5	11 (16.9)
I want additional information only if it is good news	2	2	1	5 (7.7)
I want as much information as possible, good and bad.	16	14	19	49 (75.4)
Participation				
I prefer to leave decisions about my medical care to my doctor	14	10	11	35 (53.8)
I prefer to participate in decisions about my medical care and treatment	6	10	14	30 (46.2)

Informational Support

Research Question #2. What is the quality of informational support perceived by persons with head and neck cancer?

This research question sought to explore satisfaction with informational support received throughout the cancer experience, not just in the previous 30 days (as with the identification of information needs). The quality of informational support was evaluated by measuring the participant's perceived adequacy of informational support received and the satisfaction with the way it was provided.

Perceived Adequacy of Informational Support

Participants, across all subgroups, felt they had received adequate information to meet their needs (M = 5.1). The *Kruskall-Wallis* indicated no significant difference in the perception of the adequacy of informational support among the three subgroups (p = .61). Items relating to the disease and treatment received the highest scores. The lowest rating was 4.5 for "how to meet other persons with cancer" (Table 8).

Satisfaction with Way Information was Provided

Participants were asked to rate how they felt about the way that person-to-person information was provided. This section also received high scores (M = 5.5) (Table 9).

Table 8

Mean Scores for Satisfaction with Adequacy of Informational Support Received (N = 65)

Information Item	Group A n = 20	Group B n = 20	Group C n = 25	All n = 65
Your medical condition	5.6	5.2	5.5	5.4
Treatment choices	5.5	5.5	5.5	5.5
Your treatment(s)	5.7	5.6	5.6	5.6
Possible side effects	5.2	5.3	5.2	5.3
Possible outcomes	5.5	5.3	5.3	5.3
Possible emotional reactions	4.9	4.8	4.3	4.6
How to relieve discomfort	4.7	5.5	5.0	5.1
How to cope with changes	4.8	5.1	4.9	4.9
Diet and Nutrition	5.5	5.3	4.9	5.2
Possible effects on sex life	4.3	5.2	4.9	4.8
Possible effects on soc. life	4.4	4.7	5.0	4.7
Possible effects on work life	5.1	5.0	5.0	5.0
Self-care measures	4.9	5.3	5.3	5.2
Home care services	4.8	5.0	5.4	5.1
Emotional support/Counselling	4.5	5.3	4.7	4.8
Spiritual support	4.9	5.5	5.2	5.2
Meet others with cancer	4.3	4.8	4.3	4.5
Get equipment/supplies	5.2	5.3	5.6	5.4
Financial support	4.8	4.8	3.9	4.5
Overall Satis. Mean Score	5.0	5.2	5.1	5.1

Note. Scale = 1 (Not enough) to 6 (All I needed or wanted)

Table 9

Mean Scores for Satisfaction with Way Information was Provided (N = 65)

Question	Group A n = 20	Group B n = 20	Group C n = 25	All n = 65
Were the people who gave you information sensitive to your needs?	5.8	5.6	5.4	5.6
Was the information clear?	5.8	5.5	5.2	5.4
Were you encouraged to ask questions?	5.8	5.3	5.2	5.3
If you asked questions, were they answered in a helpful way?	5.9	5.7	5.4	5.6
Overall, were you satisfied with the information received?	5.8	5.6	5.2	5.5

Note. Scale = 1 (Not very) to 6 (Very much).

Two items that asked about adequacy of information (Appendix A, Questionnaire # 10, b. and d.) were omitted from the above table because this aspect of informational support was extensively covered in Table 8 and the responses were similar.

Who Was Most Helpful?

Although indirectly related to the research question, the researcher wanted to ascertain who the participants viewed as most helpful in providing informational support. Participants could identify up to three groups (Table 10).

Table 10

Who Was Most Helpful? (N = 64)

Person(s)	Group A n = 20	Group B n = 20	Group C n = 24	All n = 65
	n	n	n	n (%)
Family/Friends	3	9	8	20 (30.8)
Nurse	13	8	8	29 (44.6)
Someone with cancer	2	2	4	8 (12.3)
Medical Specialist	19	19	22	60 (92.3)
Family Doctor	1	7	11	19 (29.2)
Social Worker	1	0	0	1 (1.5)
Clergy	1	0	0	1 (1.5)
Other	6	1	2	*9 (13.8)

(*Radiation Therapist = 6; Dietician = 3)

The medical specialist was identified as one of the most helpful by almost all participants. Less than half of the participants identified the nurse as most helpful. When

assisting participants with completion of the questionnaire, the researcher also learned that some participants thought the radiation therapists were nurses and included them in this category. Family/friends and family doctor were each identified by approximately one-third of the respondents.

Psychosocial Adjustment

Research Question #3. How well do persons with head and neck cancer adjust to their illness: a) following diagnosis, b) following treatment, and c) during rehabilitation/continuing care?

There were three components to the assessment of psychosocial adjustment: changes in roles and relationships after cancer diagnosis, emotional responses in the 30 days prior to the interview, and feelings about self at the time of the interview (Appendix A, Questionnaire #14-#21).

Roles and Relationships

For the most part, participants, across all subgroups, indicated that their roles and relationships had changed very little compared to before their illness. Domains that experienced the most change were vocational roles and social/leisure activities. These domains changed in a negative direction, indicating that cancer affected the ability to work and participate in social activities. This finding was true for all subgroups (Table 11). The *Kruskall-Wallis* indicated that there were no significant differences among the subgroups ($p = .28$) on this variable.

Table 11

Mean Scores for Adjustment in Roles and Relationships (N = 65)

Domain	Group A n = 20	Group B n = 20	Group C n = 25	All n = 65
Personal Roles	6.0	5.7	5.8	5.8
Vocational Roles	4.2	3.7	4.4	4.1
Relationship with Partner (n = 58)	5.6	5.3	5.5	5.4
Relationship with Family	5.9	5.8	5.7	5.8
Relationship with Friends	5.8	5.6	5.5	5.6
Social/Leisure Activities	4.7	4.4	4.9	4.7
Mean Role Score	5.4	5.1	5.3	5.3

Note. Scale = 1 (Very untrue) to 6 (Very true)

Respondents were also asked to identify whether their overall role function in each domain was worse (scored 1-2), about the same (scored 3-4) or better (scored 5-6) than before they had cancer (Appendix A, Questionnaire #22). Most indicated that their role functions were about the same as before they had cancer. Overall group mean role function scores improved slightly, the further the subgroup was from diagnosis (Group A: $M = 3.8$, Group B: $M = 4.3$, Group C: $M = 4.4$). All respondents attributed any changes for the worse, to their cancer.

Emotional Responses

The participants reported generally positive emotions, with all mean scores being 3 or greater, indicating that they were adjusting well emotionally. Mean emotional scores improved slightly, the further the subgroup was from diagnosis. However, the subgroup differences were not significant (*Kruskall-Wallis*, $p = .09$) (Table 12).

Table 12

Mean Scores for Emotional Responses (N = 65)

Response	Group A n = 20	Group B n = 20	Group C n = 25	All n = 65
Anxious, nervous, afraid, tense	3.9	4.4	4.6	4.3
Sad, depressed, discouraged	4.0	4.1	5.2	4.5
Angry, irritable, frustrated	4.7	4.8	4.9	4.8
Guilty, letting others down	5.7	4.7	5.6	5.3
Worried about future	3.8	4.4	4.5	4.3
*Relaxed, calm	3.0	3.2	4.5	4.2
*Happy, content	3.0	3.3	4.6	4.3
Overall Emotional Score	3.9	4.1	4.8	4.5

Note. Score = 1 (Always) to 6 (Never).

*Scores for these two items were reversed for the analysis.

Feelings About Self

Mean scores for feelings about self were also quite high, indicating generally positive feelings. For this variable, *Kruskall-Wallis* also indicated no significant differences among subgroups (p = .99) (Table 13).

Table 13

Mean Scores for Feelings about Self (N = 65)

Feeling	Group A n = 20	Group B n = 20	Group C n = 25	All n = 65
I feel good about myself	5.4	5.5	5.2	5.4
I am happy with my look	5.1	5.1	5.0	5.1
I am able to cope well	5.5	5.3	5.4	5.4
I can laugh & enjoy life	5.5	5.3	5.5	5.4
Overall Feelings Score	5.4	5.3	5.3	5.3

Note. Scale = 1 (Very untrue) to 6 (Very true)

Relationship Between Informational Support and Psychosocial Adjustment

Research Question #4. Is there a relationship between the perceived quality of informational support received and psychosocial adjustment in persons with head and neck cancer?

To assess the correlation between these two variables, the composite mean scores derived to reflect overall quality of informational support received, and overall psychosocial adjustment (as previously described) were used. Although no significant correlation was identified between informational support and adjustment in the sample as a whole, subgroups differences were apparent. Significant correlations were seen in Group B and Group C, but not in Group A (Table 14).

Table 14

Correlation Between Perceived Quality of Informational Support Received and Psychosocial Adjustment (N = 65)

	Informational Support			
Psychosocial Adjustment	Group A n = 20	Group B n = 20	Group C n = 25	Whole Group n = 65
ρ	-.18	+.51*	+.46*	+.20
p	.44	.02	.02	.11

Note. *p < .05

Further analysis of the data using *Spearman's rho* revealed significant negative correlations between psychosocial adjustment and the extent of disease at diagnosis (ρ = -.40, p = .001) and the amount of disfigurement/dysfunction (ρ = -.34, p = .005).

Summary of Results

Participants indicated they had information needs throughout the cancer experience, but mean importance scores declined, the further the subgroup was from diagnosis. The priority of specific information items also differed. For example, Group A wanted information about treatment and treatment choices, but these were no longer priority concerns for Groups B and C. Groups A and B wanted information about side effects and outcomes, but Group C was more concerned with information about diet and nutrition and how to cope with changes.

Most participants, from each subgroup, wanted to receive all information, good and bad. However, preferences for participation in decision-making differed throughout the cancer experience. Most participants in Group A preferred a passive role. As the time from diagnosis lengthened, the subgroups gradually preferred to assume a more active role, with the majority of Group C preferring to actively participate in the decision-making process.

Respondents indicated that they received all the information they needed or wanted ($\underline{M}$ = 5.1). Areas that had lower satisfaction scores were the psychosocial items, but even these scores were all above 4. Patients were also highly satisfied with the way that information was provided ($\underline{M}$ = 5.5).

For the most part, participants in all subgroups indicated that their roles and relationships had not changed following their cancer diagnosis. Vocational roles and social/leisure activities received the lowest scores, but overall, were rated as "about the same". Scores for emotional responses and self-concept were also high.

No significant correlation was shown between satisfaction with informational support received and psychosocial adjustment in the group as a whole. However, when the data were further analyzed, a significant positive relationship was found between the two variables in Groups B and C ($p = .02$). The possible meanings of this finding will be discussed in the next chapter.

CHAPTER V

Discussion

Characteristics of the Sample

Demographic Characteristics

The study sample reflects the usual demographic characteristics of persons with head and neck cancer in respect to age, gender, and education level (Cachin, 1989; Newfoundland Cancer Treatment and Research Foundation, 1994; Shah & Lydiatt, 1995; Yuska Bildstein, 1993) (Table 1). The fact that 90% of the participants are married and living with their spouse suggests that they may have a support person who can assist them with the process of adjusting to cancer. Considering the age of most participants, it is not surprising that half the sample are retired. Most others are not working or are seasonally employed.

Participants represent all areas of the province, as well as St. Pierre. Most participants are from St. John's and the Avalon, the most populated and closest areas to the cancer centre. However, when the numbers are compared to the regional populations and the provincial cancer statistics (Newfoundland Cancer Treatment and Research Foundation, 1994), they are representative of the usual population distribution and approximate the reported regional statistics for persons with head and neck cancer.

Medical Characteristics

Most patients have cancer of the throat or mouth (68%) which is in keeping with the recent provincial statistics (Newfoundland Cancer Treatment and Research Foundation, 1994). Only 28% of the sample had localized disease at the time of diagnosis. Yuska Bildstein (1993) note that more than 60% of persons with head and neck cancer have advanced disease when they first seek medical care. A large proportion of the sample (82%) have minimal to no disfigurement/dysfunction (Table 3). This may reflect recent improvements in surgical approaches and reconstructive techniques for persons with head and neck cancer (Yuska Bildstein, 1993).

Information Needs

Overall results of this study indicate a hierarchical pattern of information needs, quite similar to the findings of Derdiarian (1987a, 1987b) in a mixed group of cancer patients. In general, and especially at the time of diagnosis, information about illness, prognosis, side effects, and treatment are of greatest importance. This seems to reflect the reality that, prior to diagnosis, most patients are ill-informed about all aspects of cancer, and the provision of this information fulfils a need to know. Patients may also feel that being informed gives them some sense of control over the situation. Items related to

coping and self-care are moderately important, indicating that patients have a need to understand how they can take care of themselves. Items related to personal roles, spiritual, psychosocial and financial support, and home care services are least important. This may indicate that at that time, these needs are already being met, or are of less concern to them (Tables 5 and 6).

The overall importance of information declines the further the subgroup is from diagnosis (Table 6). Group A identify 9 of the 19 items as very important, whereas Group C fail to identify any. In contrast, Group C identify 15 of the 19 items as not very important. Group B, the middle group, identify most items (15) as of moderate importance. This probably indicates that throughout the cancer experience, participants gradually acquire needed information, and the necessity for receiving new information diminishes.

The priority of specific information items differs among the three subgroups and provides insight into the experience of cancer. For Group A, who are newly diagnosed and in Mullan's (1985) season of acute survival, primary information items relate to illness, treatment and care issues. These individuals are attempting to cope with their fears and anxieties by understanding more about their illness and its treatment. For Group B, who have completed

their treatment and are in Mullan's (1985) season of extended survival, primary concerns relate to the disease, treatment side effects and measures to relieve discomfort. At this time, they are dealing with the after-effects of treatment and are coming to grips with the realities of their situation. For Group C, who are in the phase of rehabilitation or continuing care and reflect Mullan's (1985) season of permanent survival, primary information needs are similar to, but slightly less important than Group B. Group C are also concerned with how to cope with changes, as this is a time when the secondary effects of treatment may become a principal concern. The study findings provide support for Mullan's (1985) seasons of survival and Mages and Mendelsohn's (1979) assertion that cancer is an ongoing experience that unfolds over time. In keeping with Lazarus and Folkman (1984), the results suggest that the participants' information needs reflect their appraisal of the harm, threat or challenge posed by the specific situation they are facing at the time, even though appraisal was not specifically assessed in this study.

The finding that the majority (75%) of respondents want as much information as possible (Table 7) is similar to the findings of previous studies in persons with cancer (Brandt, 1991; Cassileth et al., 1980; Davison et al., 1995; Degner & Sloan; 1992; Hack et al., 1994; Luker et al., 1995).

Participation preferences, however, change with the phase of the cancer experience. Previous studies have reported inconsistent findings regarding this variable. In light of the results of this study, the inconsistencies may be partially explained by the fact that some studies included participants across all phases of the cancer experience (Cassileth et al., 1980), while others were phase-specific (Brandt, 1991; Davison et al., 1995; Degner & Sloan; 1992; Hack et al, 1994).

Overall, 54% of the participants prefer to leave medical decisions to their doctor. The desire for a more participative role increases, the further one is from diagnosis (Table 7). At the time of diagnosis, most individuals do not have adequate information to enable them to make knowledgeable treatment decisions. The excessive threat and psychological impact of a new cancer diagnosis may also make cognitive functioning difficult. Lazarus and Folkman (1984) contend that the perceived level of threat influences one's ability to use problem-focused forms of coping, such as assimilating information and participating in decision-making. New patients may have the preconceived notion that it is the health care provider's role to make treatment decisions. As they move along the cancer continuum, they may be encouraged to participate in the decision-making process and feel more comfortable with their

health care providers. They also have time to reflect upon the cancer experience and investigate its implications and alternatives. An experience with cancer often results in personal growth and maturity that may enable individuals to assume a more active role in controlling the events of their lives. The nature of the decisions to be made may also influence the individual's desire to assume a more or less participative role in the decision-making process.

Informational Support

Respondents in this study indicate that they are very satisfied with the quality of informational support received. Satisfaction scores for both the adequacy of information (Table 8) and the sensitivity of providers (Table 9) are high. The former finding is contrary to the study findings of Glavassevich et al. (1995) and Olsen et al. (1995), who reported that patients expressed that they were inadequately prepared for surgery and possible outcomes, and to Watt-Watson and Graydon (1995) who noted that head and neck cancer patients in their sample requested more information about prognosis, activity and continued care. The contradictory results may reflect a more sensitive approach to the assessment of information needs and the provision of informational support in the study setting compared to the settings in the other studies.

For the most part, highest scores for satisfaction with information received related to medical care and treatment. These are information areas primarily communicated by physicians. This finding was supported by the results (Table 10). Ninety-two per cent of the respondents identified the doctor as one of the most helpful individuals/groups. The nurse was mentioned second, but was identified by considerably fewer respondents (45%). As stated in the results chapter, the responses concerning nurses may also have included radiation therapists. Considering that respondents could, and usually did, identify up to three groups of individuals who were most helpful, this is somewhat concerning and has implications for nursing.

Steptoe et al. (1991) and Weisman (1979) contended that conveying information to patients with cancer was important, provided it was communicated with caring and compassion. The high scores for both adequacy and sensitivity of informational support indicate that this is something the care providers do well. Lazarus and Folkman (1984) noted that the ways people cope depends heavily on the resources available to them and the context of the specific encounter.

Psychosocial Adjustment

The mean scores for psychosocial adjustment, for all subgroups, indicate that head and neck cancer has caused

little change in participants' lives and that they are adjusting quite well (Tables 11-13). This finding is supported by some researchers (Baker, 1992; Gamba et al., 1993;, Olsen et al., 1995), but does not reflect the adjustment problems reported by others (Pruyn et al., 1986; Rapoport et al., 1993). The findings suggest that the participants in this study were able to appraise their unique situations and use available coping resources to manage the changing demands of their cancer experience (Lazarus & Folkman, 1984). The positive psychosocial adjustment may also be due to the low degree of disfigurement/dysfunction suffered by this sample. Persons with greater disfigurement/dysfunction indicate more problems with adjustment. This observation supports the findings of Dropkin and Scott (1983), Gamba et al. (1992), and Olsen et al. (1995). Other factors affecting adjustment such as personality, family support, and spiritual strength may be at play, but were not measured. It is also noted that studies used different research instruments and this measurement factor could account for variations in the reported results.

Similar to findings of Northouse (1990) and Watt-Watson and Graydon (1995), this study indicates that the domains of vocational roles and social/leisure activities experience the most change following cancer. Changes tend to persist

throughout the cancer experience, but are greatest for Group B (Table 11). Individuals in Group B recently completed their course of treatment and are more subject to treatment after-effects. One might expect Group A, who have just been diagnosed, to exhibit the most change, however, this is not the case. This may be because the treatment after-effects, particularly from radiation, have not had much impact yet.

All subgroups reported a slight improvement in their relationships with partner, family and friends, compared to before having cancer ($\underline{M}$ = 4.6). This may reflect the support that is often rallied around individuals who are diagnosed with cancer, or it may reveal the closeness typical of Newfoundland families. While the researcher was assisting some participants with questionnaire completion, several described how cancer had brought the family closer together. Olsen et al. (1995) found that their study sample of post-surgical head and neck cancer patients also obtained high scores for relationships with spouse and family.

Head and neck cancer has been described as being very emotionally traumatic (Dropkin, 1989; Mah & Johnston, 1993). The study findings do not support this contention. The mean scores across the three subgroups for all emotional responses are high (Table 12). Group A exhibit the lowest mean score, which probably reflects the stress of a new cancer diagnosis. However, an overall mean emotional score

of 3.9, suggests that Group A are able to keep negative emotions in balance. The data indicate a gradual, though not statistically significant, improvement in mean emotional scores (3.9-4.5) the further the subgroup is from diagnosis. This does not support the finding of Rapoport et al. (1993), that the psychosocial problems of persons with head and neck cancer exacerbate with time. However, Rapoport's (1993) sample included patients as long as 21 years after diagnosis, so it may take many years for psychological deterioration to become apparent. It is also possible that the expression of positive emotions reflects the use of denial and other defense mechanisms, in the face of a threatening illness.

Diminished self-concept has been identified as a consequence of the body image changes that may result from head and neck cancer and its treatment (Dropkin, 1989; Gamba et al., 1992; Glavassevich et al., 1995; Koster & Bergsma, 1990; Pruyn et al., 1986). The significant negative correlation found between psychosocial adjustment and the amount of disfigurement/dysfunction in this study, supports this contention. On the whole, however, the mean self-concept scores for all subgroups are high (Range = 5.3-5.4) (Table 13). This may be because the majority of the sample have minimal disfigurement or dysfunction (Table 4). Lazarus and Folkman (1984) asserted that the ability to cope

effectively as an event unfolds is of crucial importance to sustain long-term morale (how people felt about themselves).

Informational Support and Psychosocial Adjustment

A significant positive correlation between the quality of informational support received and psychosocial adjustment is demonstrated in Groups B and C, but not in Group A (Table 14). Individuals in Group A are still experiencing the initial crisis of cancer, as identified by Mullan (1985). It may be too early to assess psychosocial adjustment (Gamba et al., 1992). A few respondents in Group A admitted to having difficulty with items that related to personal, vocational and social functioning, as they were still in a phase of active treatment or just recovering from surgery. It may also be that psychosocial adjustment related to information received during the initial phase of cancer does not become apparent until later in the course of the disease. Other factors, such as family support, competent medical care, and individual coping abilities may play a greater role in promoting adjustment at this time.

It would seem that information assists one's coping efforts and contributes to overall psychosocial adjustment, although the results need to be interpreted with caution. It is noted that the correlation between informational support and psychosocial adjustment found in Groups B and C does not imply a cause and effect relationship. However,

the high significance values (.02), lead one to believe that the finding is meaningful.

Summary of Discussion

Study participants, at all three phases of the cancer experience, indicate that they want to be well informed. In the early phase of head and neck cancer, receiving information is paramount, however, it assumes less importance, as the length of time from diagnosis increases among the subgroups. This may reflect a lessening of the threats of initial diagnosis and/or an assimilation of the events into one's life. The priority of specific information needs also differs among the subgroups and reflects the harms, threats or challenges associated with each phase of the experience.

As individuals move further away from diagnosis, they prefer to take on a more active role in decision-making. This difference may reflect a number of factors including increased knowledge, more time for reflection, lowered level of threat, better relationship with health care providers, and decreased overall stress associated with head and neck cancer.

In spite of the potential impact of head and neck cancer, participants indicate very little change in the psychosocial dimensions of their lives. It seems they are

able to mobilize their coping efforts and have the resources to successfully manage the demands of their illness.

There is a significant positive correlation between satisfaction with informational support received and psychosocial adjustment in Groups B and C. This suggests that providing information helps individuals in the appraisal process and ultimately in the adjustment to head and neck cancer. The lack of a significant correlation in Group A may be because adjustment associated with informational support is not manifested until later in the course of the cancer experience.

Relevance of Findings to Theoretical Framework

The study findings support several of the assertions made by Lazarus and Folkman (1984) in their theory of stress, appraisal and coping.

In keeping with Lazarus and Folkman's thinking, the findings indicate that the priority of information needs varies and reflects appraisal of the changed circumstances at different phases of the cancer experience. Group A, who are most recently diagnosed, clearly attach a higher overall importance to information than do the other two subgroups. This finding provides support for Lazarus and Folkman's postulation that information seeking is often the first coping mode used in a new and stressful situation. The majority of Group A also prefer a passive role in decision-

making. This may be because their perceived stress is so great that cognitive functioning is impaired.

On the whole, the participants in this study are adjusting well to their cancer. They also indicate good relationships with their family and friends and perceive that they are receiving adequate and sensitive informational support. A significant positive correlation is shown between informational support and psychosocial adjustment. These findings lend support to Lazarus and Folkman's assertion that the way people cope depends heavily on the resources available to them.

In summary, Lazarus and Folkman's (1984) theory of stress, appraisal and coping provided a useful framework for this study.

Limitations

Although this study was implemented in such a way as to minimize limitations, some potential sources of bias exist which limit generalization of the results.

Individuals who seek more information and involvement in their care may have been more likely to agree to participate in the study. Individuals who were highly stressed or feeling unwell, may not have participated, although they had needs and concerns that should be captured by the study. Some participants may not have answered as honestly as they could, fearing it might jeopardize their

patient/nurse or doctor relationship and ultimately their care. Factors inherent in the participants' reason for being in hospital or visiting the clinic setting may have affected their level of anxiety and consequently their responses.

The questionnaire used in this study was a new tool. It has a high alpha level of reliability, but was quite lengthy. Although it was designed for self-administration, many participants preferred the researcher to administer the questionnaire. The researcher noted that the closer participants were to their diagnosis, the more they preferred the researcher's assistance. It was realized during the conduct of this study that some of the psychosocial items relating to roles and relationships were difficult for participants in Group A to respond to, because of the early phase of their cancer experience. There was no mid-point on the Likert-type rating scale. This was done intentionally, but it was observed that most respondents chose 4 rather than 3 as the mid-point. A 5 or 7-point Likert scale may be more appropriate. The tool may also have lacked the sensitivity to discriminate between subtle differences in items reflecting information needs or psychosocial adjustment, resulting in most responses being skewed to 5 and 6. Furthermore, it was noted that human thinking and emotions were difficult to measure using

numbers that might not accurately reflect all dimensions of the processes.

This study focused on the role of informational support in psychosocial adjustment. Although informational support may be a critical element in adjustment, other factors, such as coping abilities, previous life experiences and family support also play important roles in the process. The latter factors were not measured in this study, thus their impact on adjustment is not known.

This was a cross-sectional design, so that comparisons were made between different subgroups of individuals. It was not known how similar these subgroups were on all variables prior to their diagnosis. Because this was a correlational study, associations could be drawn between informational support and psychosocial adjustment, but no cause and effect relationship concluded. The sample size was relatively small, which limited the statistical power of inferential analyses and calculations of internal reliability coefficients.

CHAPTER VI

Implications and Conclusion

Implications for Nursing Practice

The findings of this study suggest the value of informational support in assisting individuals in their adjustment to cancer, and indicate that most respondents want to be well-informed. Nurses, who are front-line health care providers and have the most contact with patients, could be leaders in the coordination and delivery of patient information and education services. Patient education should be a priority concern and part of nursing care planning.

The study findings highlight the importance of assessing individual information needs and integrating the provision of information into total patient care. Although there are some commonalities, the findings indicate that the information needs of persons with head and neck cancer differ throughout the phases of the cancer experience. Those who are newly diagnosed warrant special consideration, however, individuals, across all phases, have information needs. The latter finding highlights the need for ongoing assessment and intervention.

A plan for patient education should be sensitive to individual information preferences, and should consider phase-specific priority concerns. It would be helpful if

nurses had a formalized way of knowing specific information needs and what information should be provided, as patients move along the cancer continuum. One method of doing this is with a checklist attached to the patient's chart. This document could remind nurses of relevant content areas, and would serve as a communication tool to enhance continuity of care among collaborating health care providers. Luker et al. (1995) suggested developing a profile of information needs that could be used to assist nurses in tailoring information to individual needs. Patients could also keep a diary of their concerns, and share this information with health care providers, throughout their cancer experience.

In recent years there has been much emphasis on empowering patients and including them as part of the health care team. Patients should have the opportunity to be involved in decision-making, at the appropriate times and at the level they desire. Information giving is an essential element in preparing individuals to be active participants in their care. In partnership with their patients, nurses should assess patients' information needs, and should also use their findings to mutually make knowledgeable and confident decisions about their care.

Although nurses were identified as the second most helpful information provider in this study, they were mentioned by less than half of the respondents. This

finding provides an incentive for improvement, through both individual efforts and enhanced collaboration with the medical specialists. The participants in this study did not identify deficient areas of information, but other studies noted that patients wanted more information about possible outcomes, activity and continued care. These are information areas that nurses are well equipped to address.

The study findings indicate that most individuals adjusted well to head and neck cancer, but this should not diminish the attention given to assessing psychosocial domains and supporting individuals in their adjustment efforts. Persons with more extensive disease and greater disfigurement/dysfunction from head and neck cancer indicated more adjustment difficulties. It is important that nurses consider their special needs and provide extra support to assist them in the coping process.

An encouraging finding of the study was that participants viewed their health care providers as compassionate and helpful. These findings should inspire nurses and doctors to continue these valued interpersonal approaches in their daily interactions with patients.

Implications for Nursing Education

The findings of this study, i.e., information needs change among subgroups, depending on the length of time since diagnosis, reinforce the principle that each person's

needs are unique, even among those experiencing the same diagnosis. The emphasis on individual differences is introduced in basic nursing education programs, should continue to be enhanced in graduate nursing practice. Continuing education programs should be offered to update nurses as new theories and approaches to information-giving evolve. Inservice sessions could help nurses understand the changing needs throughout the cancer experience, and identify the unique information needs and psychosocial concerns of persons with head and neck cancer. Research reports, such as this one, could be shared with nurses caring for persons with head and neck cancer. Even experienced nurses should find the information beneficial. At the very least, it would strengthen beliefs they already hold and reinforce the way they already practice.

Implications for Research

This study could be replicated in other populations, particularly populations with other site specific cancers. Comparisons of findings and their implications could then be undertaken between different site specific cancer populations.

Research could be done to assess the most effective modes of providing information to persons with cancer and ascertain how they view the roles of the different health professionals in providing information.

Other social support needs of persons with head and neck cancer could be investigated. It would seem appropriate to start with emotional support since this seems to be an area of special concern in this population. Coping strategies used by this population could also be investigated, possibly using The Ways of Coping Questionnaire developed by Lazarus and Folkman (1984).

In contrast to other reported studies, the participants in this study had high adjustment scores. It would be interesting to explore what effect various factors, such as cultural variables and social support, have on psychosocial adaptation to cancer.

This study yielded much data that could be further analyzed. A secondary analysis of data could be undertaken to explore interrelationships among a wide variety of variables. The data from this study could also be further analyzed to determine whether a simpler, more practical, but meaningful tool could be developed. This new tool could be routinely used to assess information needs of persons with cancer and identify individuals having adjustment difficulties, as a basis for care planning.

A longitudinal study in persons with head and neck cancer could be undertaken to examine changes over time in

the same participants. A qualitative study could explore, in more depth, the subtle concerns of this group, that may have been missed by a quantitative design.

Conclusion

The findings of this study indicate that persons with head and neck cancer have information needs throughout the course of their cancer experience, and want to be well informed. Although study participants generally reported high levels of satisfaction with informational support received, some areas of information might be enhanced. Nurses could take a proactive role in providing information services to meet the needs of persons with head and neck cancer. The participants indicated that, on the whole, they are adjusting to changes imposed by their cancer, but this doesn't diminish the need for ongoing assessment and support.

Changes presently taking place within the health care system are making it increasingly important that nurses use limited time to the patients' best advantage. This study provides concrete data that can serve as a foundation for planning teaching approaches and building patient information programs to meet the needs of persons throughout their experience with head and neck cancer.

The significant positive correlation shown between informational support and psychosocial adjustment in Groups B and C, suggests that informational support assists individuals in the process of adjusting to head and neck cancer. The results of this study are especially meaningful, considering the present emphasis on outcomes of

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APPENDICES

(Note: Size of print is reduced for binding)

INFORMATIONAL SUPPORT

AND PSYCHOSOCIAL ADJUSTMENT

IN PERSONS WITH HEAD AND NECK CANCER

We need your help!

We would like to know what information you feel you need to help you cope with cancer, how well you feel your needs are being met, and how you are adjusting to cancer and its effects on your life. The purpose of this study is to give us information that will help us learn how we can improve the ways we provide information to people with cancer, like yourself.

This questionnaire consists of three parts. The first part asks you some general information about yourself. The second part asks you about your information needs and how you feel about the information you have received. The third part asks you about how cancer has affected your personal and social life, your relationships with others, and your emotions. The questionnaire should take about 20 minutes to complete.

Please answer all the questions as honestly as you can.

All your responses will be kept confidential.

Administered by:_____ Date: ____/____/____

Setting:_____ Code No: _____

SECTION 1

BACKGROUND INFORMATION

1. What is your gender? 1 ___ Male 2 ___ Female

2. What is your age group? 1 ___ 16-24 3 ___ 35-49 5 ___ 65-79
2 ___ 25-34 4 ___ 50-64 6 ___ 80 and over

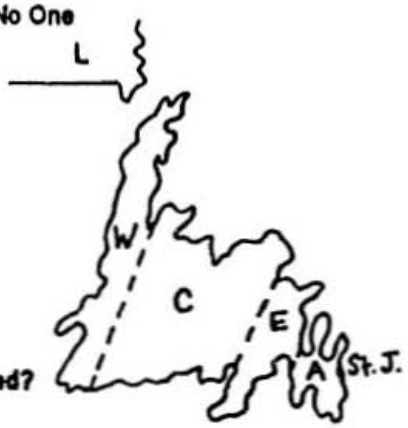
3. What is your marital status? 1 ___ Married/Common law 3 ___ Widowed
2 ___ Divorced/Separated 4 ___ Single, never married

4. Who do you live with? (✓ all that apply)

1 ___ Husband/Wife/Spouse 3 ___ Brother/Sister 5 ___ Other Relative/Friend
2 ___ Son/Daughter 4 ___ Grandchildren 6 ___ No One

5. Where in Newfoundland do you live?

1 ___ Labrador 4 ___ Eastern
2 ___ Western 5 ___ Avalon
3 ___ Central 6 ___ Metropolitan St. John's



6. What is the highest level of formal schooling you have completed?
(other than courses of less than one year)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 20+

7. Are you working/attending school? (✓ all that apply)

1 ___ Full time 3 ___ Homemaker 5 ___ Seasonal
2 ___ Part time 4 ___ Retired 6 ___ Not working

SECTION 2

INFORMATION NEEDS

8. In the past 30 days, how important to you was information about each of the following areas?
(Circle one response for each item)

	Does Not Apply	Not Important		Somewhat Important		Very Important	
a) Your medical condition	0	1	2	3	4	5	6
b) Treatment choices available to you	0	1	2	3	4	5	6
c) Your treatment(s)	0	1	2	3	4	5	6
d) Possible side effects of your treatment(s)	0	1	2	3	4	5	6
e) Possible outcomes of your treatment(s)	0	1	2	3	4	5	6
f) Possible emotional reactions (eg. anxiety, fear, depression)	0	1	2	3	4	5	6
g) How to relieve physical discomfort (eg. pain, dry mouth)	0	1	2	3	4	5	6
h) How to cope with physical changes	0	1	2	3	4	5	6
i) Diet and nutrition	0	1	2	3	4	5	6
j) Possible effects on your sex life	0	1	2	3	4	5	6
k) Possible effects on your social life	0	1	2	3	4	5	6
l) Possible effects on your work life	0	1	2	3	4	5	6
m) Self - care measures at home	0	1	2	3	4	5	6
n) Home care services available	0	1	2	3	4	5	6
o) Emotional support/Counselling services	0	1	2	3	4	5	6
p) Spiritual support	0	1	2	3	4	5	6
q) How to meet other people with cancer	0	1	2	3	4	5	6
r) Where or how to get equipment/supplies	0	1	2	3	4	5	6
s) Financial support available	0	1	2	3	4	5	6
t) Other (Specify):_____	0	1	2	3	4	5	6

SECTION 3

INFORMATIONAL SUPPORT

9. Since your illness, how much information did you get in the following areas?
(Circle one response for each item)

	Does Not Apply	Not Enough		Some			All I needed or wanted
a) Your medical condition	0	1	2	3	4	5	6
b) Treatment choices available to you	0	1	2	3	4	5	6
c) Your treatment(s)	0	1	2	3	4	5	6
d) Possible side effects of your treatment(s)	0	1	2	3	4	5	6
e) Possible outcomes of your treatment(s)	0	1	2	3	4	5	6
f) Possible emotional reactions (eg. anxiety, fear, depression)	0	1	2	3	4	5	6
g) How to relieve physical discomfort (eg. pain, dry mouth)	0	1	2	3	4	5	6
h) How to cope with physical changes	0	1	2	3	4	5	6
i) Diet and nutrition	0	1	2	3	4	5	6
j) Possible effects on your sex life	0	1	2	3	4	5	6
k) Possible effects on your social life	0	1	2	3	4	5	6
l) Possible effects on your work life	0	1	2	3	4	5	6
m) Self - care measures at home	0	1	2	3	4	5	6
n) Home care services available	0	1	2	3	4	5	6
o) Emotional support/Counselling services	0	1	2	3	4	5	6
p) Spiritual support	0	1	2	3	4	5	6
q) How to meet other people with cancer	0	1	2	3	4	5	6
r) Where or how to get equipment/supplies	0	1	2	3	4	5	6
s) Financial support available	0	1	2	3	4	5	6
t) Other (Specify):_____	0	1	2	3	4	5	6

10. Please rate how you feel about information you received.
(Circle one response for each item)

	Not Very			Somewhat		Very Much
a) Were the people who gave you information sensitive to your needs?	1	2	3	4	5	6
b) Did the information meet your needs?	1	2	3	4	5	6
c) Was the information clear?	1	2	3	4	5	6
d) Did you get enough information?	1	2	3	4	5	6
e) Were you encouraged to ask questions?	1	2	3	4	5	6
f) If you asked questions, were they answered in a helpful way?	1	2	3	4	5	6
g) Overall, were you satisfied with the information you received?	1	2	3	4	5	6

11. Who was most helpful in giving you the information you needed? (✓ up to three)

1 ___ Family/Friends
2 ___ Nurse
3 ___ Someone else with cancer
4 ___ Medical Specialist
5 ___ Family Doctor
6 ___ Social Worker
7 ___ Clergy
8 ___ Other (Specify):_____

SECTION 4

PARTICIPATION AND INFORMATION PREFERENCES (✓ one response for each item)

12. a) Which statement describes you best?

1 ___ I prefer to leave decisions about my medical care to my doctor.

2 ___ I prefer to participate in decisions about my medical care and treatment.

b) Which statement describes you best?

1 ___ I want only the information needed to care for myself properly.

2 I want additional information only if it is good news.

3 ___ I want as much information as possible, good and bad.

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SECTION 5

GENERAL INFORMATION

13. In general, how would you rate the following ways of providing information to people with cancer like yourself? (Circle one response for each item)

	Not Helpful			Somewhat Helpful		Very Helpful
a) Person to person talks	1	2	3	4	5	6
b) Discussion groups on cancer	1	2	3	4	5	6
c) Written information	1	2	3	4	5	6
d) Videotapes/Movies	1	2	3	4	5	6
e) Cancer information hotline	1	2	3	4	5	6

SECTION 6

PSYCHOSOCIAL ADJUSTMENT

In the past 30 days, how true are these statements for you? (Circle one response for each item)

14. Personal Roles

Compared to before my illness:

	Very Untrue			Somewhat True		Very True
a) I pay as close or closer attention to my health	1	2	3	4	5	6
b) I am as able to care for my personal needs, like dressing, bathing and toileting.	1	2	3	4	5	6
c) I do as much of my own self-care	1	2	3	4	5	6

15. Vocational Roles (Job, Housework, School)

Compared to before my illness:

	Very Untrue			Somewhat True		Very True
a) I am able to perform my usual work	1	2	3	4	5	6
b) I am able to work as long	1	2	3	4	5	6
c) I am able to work as hard	1	2	3	4	5	6

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16. Relationship with Partner (Husband, Wife, Spouse) *Skip this section if it does not apply

Compared to before my illness:	Very Untrue			Somewhat True		Very True
a) Our relationship is the same or better	1	2	3	4	5	6
b) We communicate the same or better	1	2	3	4	5	6
c) Our sexual relationship is the same or better	1	2	3	4	5	6
d) We do the usual activities with each other, like going out or doing things together.	1	2	3	4	5	6
e) I get the same or more support	1	2	3	4	5	6

17. Relationship with Other Family Members (Children, Parents, Brothers, Sisters, etc.)

Compared to before my illness:	Very Untrue			Somewhat True		Very True
a) My relationship with my family is the same or better	1	2	3	4	5	6
b) Communication with my family is the same or better	1	2	3	4	5	6
c) I have the same or more contact with my family	1	2	3	4	5	6
d) My family gives me the same or more support	1	2	3	4	5	6

18. Relationship with Friends

Compared to before my illness:	Very Untrue			Somewhat True		Very True
a) My relationship with my friends is the same or better	1	2	3	4	5	6
b) Communication with my friends is the same or better	1	2	3	4	5	6
c) I have the same or more contact with my friends	1	2	3	4	5	6
d) My friends give me the same or more support	1	2	3	4	5	6

19. Social/Leisure Activities

Compared to before my illness:	Very Untrue			Somewhat True		Very True
a) I do the same social/leisure activities	1	2	3	4	5	6
b) I enjoy social/leisure activities the same or more	1	2	3	4	5	6

20. Emotional Responses

In the past 30 days, how often have you felt:	Always			Sometimes		Never
a) Anxious, nervous, afraid, tense?	1	2	3	4	5	6
b) Sad, depressed, discouraged?	1	2	3	4	5	6
c) Angry, irritable, frustrated?	1	2	3	4	5	6
d) Guilty for letting others down?	1	2	3	4	5	6
e) Worried about the future?	1	2	3	4	5	6
f) Relaxed, calm?	1	2	3	4	5	6
g) Happy, content?	1	2	3	4	5	6

21. Feelings about Self

At the present time:	Very Untrue			Somewhat True		Very True
a) I feel good about myself	1	2	3	4	5	6
b) I am happy with the way I look	1	2	3	4	5	6
c) I am able to cope well	1	2	3	4	5	6
d) I am able to laugh and enjoy life	1	2	3	4	5	6

22. Overall Functioning

Compared to before my illness, I would say that:	Worse			About the Same		Better
a) My personal care is	1	2	3	4	5	6
b) My ability to work is	1	2	3	4	5	6
c) My relationship with my partner is	1	2	3	4	5	6
d) My relationship with my family is	1	2	3	4	5	6
e) My relationship with my friends is	1	2	3	4	5	6
f) My involvement in social activities is	1	2	3	4	5	6
g) My emotional well-being is	1	2	3	4	5	6
h) My feelings about myself are	1	2	3	4	5	6

i) If things are worse, do you feel it is because of: **(Omit if this does not apply)**

1 ___ Your cancer 2 ___ Other reason(s)

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SECTION 7

OTHER INFORMATION

23. Is there anything else you would like to add about your experience that would help us in planning to meet the needs of other people like you?

YOU ARE NOW FINISHED.

THANK YOU VERY MUCH FOR COMPLETING THIS SURVEY

-9-

SECTION 8

Code No:_____

MEDICAL INFORMATION - To be completed by researcher

24. Phase of cancer experience:

1 ___ Post Dx 2 ___ Post Tx 3 ___ Rehab/Cont.Care

25. Diagnosis by site:

1 ___ Throat 2 ___ Nasopharynx 3 ___ Salivary glands

4 ___ Mouth 5 ___ Skin 6 ___ Other

26. Disease Status:

1 ___ Initial Disease 2 ___ Recurrence

27. Extent of Disease at Diagnosis (or at Initial Recurrence):

2 ___ Localized 3 ___ Regional Extension

4 ___ Extensive Tumour 5 ___ Node Involvement 6 ___ Distant Metastasis

28. Present Extent of Disease:

1 ___ Eliminated 2 ___ Localized 3 ___ Regional Extension

4 ___ Massive Tumour 5 ___ Node Involvement 6 ___ Distant Mets

29. Treatments (Present or Past):

1 ___ Chemotherapy 3 ___ Surgery

2 ___ Radiotherapy 4 ___ Other(Specify):_____

30. Total Disfigurement/Dysfunction:

1 ___ None 2 ___ Minimal 3 ___ Moderate 4 ___ Severe

Appendix B

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine, The Health Sciences Centre

January 23, 1995

TO: Ms. Barbara Adams

FROM: Dr. Verna M. Skanes, Assistant Dean,
Research and Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee #94.153

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled **"Informational Support and Psychosocial Adjustment in Persons with Head and Neck Cancer"**.

Full approval has been granted from point of view of ethics as defined in the terms of reference of this Faculty Committee.

It will be your responsibility to seek necessary approval from the hospital(s) wherein the investigation will be conducted.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

Verna M. Skanes, Ph.D.
Assistant Dean

VS\jglo

cc: Dr. K.M.W. Keough, Vice-President (Research)
Dr. Maureen Dunn, Chairperson, Ethics Committee, Grace Hospital
Ms. Denise Dunn, c/o Medical Director's Office, Grace Hospital
Dr. Ford Bursey, General Hospital Representative, HIC
Dr. Eric Parsons, Medical Director, General Hospital
Dr. Lan Gien, Supervisor

building hope together

March 13, 1995

Ms. Barbara Adams
18 Charlottetown Place
St. John's, NF
A1A 2P4

Dear Barbara:

As per our telephone conversation, please be advised administrative approval was given for you to proceed with your study following approval of your project by the Human Investigation Committee.

Yours truly,

Bertha H. Paulse
Chief Executive Officer

BHP/eds

Newfoundland Cancer Treatment and Research Foundation
Dr. H. Bliss Murphy Cancer Centre 300 Prince Philip Drive St. John's NF A1B 3V6 Tel: (709) 737-6480 Fax: (709) 751-0827

THE GENERAL HOSPITAL

300 Prince Philip Drive
St. John's, Nfld. Canada A1B 3V6

Health Sciences Centre
Telephone: (709) 737-6300
Fax: (709) 737-6400
Office: (709) 737-

Dr. L. A. Miller Centre
Telephone: (709) 737-6555
Fax: (709) 737-6969
Office: (709) 737-

1995 03 24

TO: Ms. Barbara Adams

FROM: Chief Executive Officer & Medical Director

SUBJECT: "Informational Support and Psychosocial Adjustment i Persons with Head and Neck Cancer", #94-153.

This letter is to formally inform you that the Board of Directors of the General Hospital has recently approved your above investigation on recommendation of the Medical Advisory Committee.

The General Hospital in cooperation with Memorial University is implementing the proposal where contract research will be assessed an amount for indirect costs to the institutions. The approval to conduct this research is contingent on the preparations of formal budgets and when the investigation is being done on the request of a pharmaceutical company and others where responsibility and ownership of the data is their's these indirect costs (overhead) will be charged. You may be contacted in the near future by a representative of the hospital or university for review of your budgets and possible assessment.

GLADYS PEACHEY
Chief Executive Officer

ERP/sh
c.c. Linda Purchase

WILLIAM AND
CATHERINE BOOTH
Founders
PAUL A. RADER
General
DONALD V. KERR
Territorial Commander

THE SALVATION ARMY

GRACE GENERAL HOSPITAL
241 LeMARCHANT RD., ST. JOHN'S, NEWFOUNDLAND • A1E 1P9 • TEL: 778-6222

1995 04 03

Ms. Barbara Adams
18 Charlottetown Place
St. John's, NF
A1A 2P4

Dear Ms. Adams:

RE: INFORMATIONAL SUPPORT AND PSYCHOSOCIAL ADJUSTMENT IN PERSONS WITH HEAD AND NECK CANCER, REFERENCE NUMBER 94.153

Following upon the recommendation of the Human Investigation Committee and the Medical Advisory Committee, the Board of Management at the Grace General Hospital has approved your proposed investigation entitled *"Informational Support and Psychosocial Adjustment in Persons with Head and Neck Cancer"*.

This approval is subject to the provisions of the letter from the Human Investigation Committee of the Faculty of Medicine and has been granted from the point of view of ethics as defined in the Terms and Reference of the Faculty Committee.

Notwithstanding the approval of the Human Investigation Committee, the primary responsibility of the ethical content of the investigation remains with you.

Please inform all other participants of this approval.

A copy of your findings and report would be appreciated.

Yours sincerely,

N.J. Kush, MD FRCP(C)
Medical Director

/dd

cc: Dr. Maureen Dunne
Chairperson
Human Investigation Committee

Appendix C

RESEARCH STUDY: OVERVIEW

Researcher:	Barbara Adams, Graduate Student School of Nursing, M. U. N.
Title:	Informational Support and Psychosocial Adjustment in Persons with Head and Neck Cancer
Background:	Topic selection was based on information yielded from the national study undertaken by the Canadian Cancer Society (1992), the focus groups conducted by the N.C.T.R.F. (1994), and needs identified by persons involved with cancer care.
Goals:	1) To identify the information needs of persons with head and neck cancer, yielding concrete data that can be used in planning formal and informal educational programs. 3) To assess the present level of informational support perceived by the study population. 3) To examine the outcome measure of psychosocial adjustment, and assess whether there is any relationship between adjustment and perceived satisfaction with information recieved.
Participants:	Persons diagnosed with head and neck cancer, at three points in time (cross-sectional study). i) Within three months of diagnosis, ii) Within three months of completion of treatment, iii) 12 to 24 months following diagnosis.
Accrual:	a) Through Cancer Centre b) Through E.N.T. unit of S.A.G.G.H.
Method:	a) Self-Administered questionnaire b) Brief interview
Procedure:	1) Researcher will meet potential participants, explain study, and obtain consent. 2) Interview will be conducted, either a) during clinic visit, preferably before seeing physician, or b) in hospital.

Appendix D

RESEARCH PROJECT

Information Needs and Adjustment

In Persons with Head and Neck Cancer

Sample Verbal Introduction

Barbara Adams, a cancer nurse and graduate nursing student, is conducting a study to identify the information needs and adjustment concerns of people who have head and neck cancer. The information will be valuable in program planning. She would like to meet with you to discuss this further. May I give her your name?

For Your Information:

I will explain the study to those who are willing to speak with me, but if they have a few preliminary questions here is some general information.

- the study is a "one-shot" deal
- it involves a questionnaire that is self-administered, if able, or researcher assisted, if needed
- the questionnaire is completed at the time (not taken home)
- the questionnaire takes 15-20 minutes to complete

Thanks,

Appendix B

Information about Study

Study: Informational Support and Psychosocial Adjustment in Persons with Head and Neck Cancer

Researcher: Barbara Adams, BNSc, RN

You have been selected to take part in a research study. **Participation is entirely voluntary.**

The purposes of this study are to:

1) Identify your information needs.

2) Find out how well you feel your information needs have been met.

3) Assess what effects cancer has had on your life.

4) Determine if there is any relationship between the informational support you received and your adjustment to cancer.

The results of this study will help us develop better programs to meet the information needs of people with head and neck cancer. You may not benefit directly by taking part in this study, but you will be helping other people, like yourself.

The researcher will speak with you briefly, and ask you to complete a questionnaire. The questionnaire asks you about the kinds of information you feel you need or want to help you cope with your cancer, how you feel about the information you have received, and how cancer has affected your personal and social life, your relationships with others, and your emotions. The questionnaire should take 15 to 20 minutes to complete. The researcher will also review your chart for basic medical information.

Whether you decide to participate or not to participate will in no way affect the care you are receiving. All information will be kept confidential. Your name will not be used on any paper. Your responses will be put together with those of others and there will be no way that theycan be identified.

Appendix F

Consent to participate

Study: Informational Support and Psychosocial Adjustment in Persons with Head and Neck Cancer

I,_____ agree to participate in this research study.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that I may not benefit from my involvement. I acknowledge that a copy of this form has been given to me.

_____ _____
(Signature of Participant) (Date)

_____ _____
(Signature of Witness) (Date)

To the best of my ability I have fully explained the nature of this research study to the participant. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

_____ _____
(Signature of Researcher) (Date)

Phone number_____